APPENDIX

Plaintiffs' First Amended Complaint, Filed July 14, 1986 ..... A-1 to -34

Richard H. Gross, et al., Early Management and Decision Making for the Treatment of Myelomeningocele, 72 Pediatrics 450 (1983) ..... A-35 to -55

Order Granting Defendants' Motion to Dismiss, Entered June 23, 1987 ..... A-56 to -57

Minute Order Correcting the Order Granting Defendants' Motion to Dismiss, Entered June 29, 1987 ..... A-58

Final Judgment by Jury Verdict, Entered Feb. 8, 1990 . A-59

Amended Order of Final Judgment, Entered May 9, 1990 ..... A-60 to -61

Opinion and Judgment of Tenth Circuit Court of Appeals, Entered Aug. 6, 1992 ..... A-62 to -82

IN THE UNITED STATES DISTRICT COURT FOR THE WESTERN DISTRICT OF OKLAHOMA

CARLTON JOHNSON by SHARON JOHNSON as his next friend; SHARON JOHNSON: STONEWALL JACKSON SMITH, deceased, by and through FRIEDA SMITH and JOHN SMITH; MELISSA CAMP, deceased, by and through CHEPARNEY CAMP; THE SPINA BIFIDA ASSOCIATION OF AMERICA: and THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS; individually and on behalf of others similarly situated,

Plaintiffs,

v.

RICHARD H. GROSS, M.D., in his individual capacity; J. ANDREW SULLIVAN, M.D., DAVID YNGVE, M.D., WILLIAM BARNES, M.D., HARRIET COUSSONS, M.D., LAURA TULL, R.N., RUTH TATYREK, M.S.W., all in their individual and official capacities; WEBB THOMPSON, M.D., Chief of Staff and Medical Director, Oklahoma Children's Memorial Hospital, in his individual and official capacity; DANIEL DOENITY, Administrator, Oklahoma Children's Memo-

FILED
July 14, 1986
Robert D. Dennis,
Clerk
U.S. District Court
by _____
Deputy

No. CIV-85-2434-A

rial Hospital, in his individual and)
official capacities, JERRY D.)
RAZOOK, M.D., Attending)
Assistant Professor of Pediatrics,)
Pediatric Cardiology Service,)
Oklahoma Children's Memorial Hos-)
pital, in his individual capacity; GRE-)
GORY HERBECK, M.D., Intern)
Department of Pediatrics, Oklahoma)
Children's Memorial Hospital, in his)
individual capacity; ANTONIO)
PADILLA, Chief Executive Officer,)
Oklahoma Teaching Hospitals, in his)
individual and and official capacities;)
ROBERT FULTON, Director of)
Human Services in his individual and)
official capacities; REGINALD)
BARNES, W.E. FARHAS,)
ALBERT FURR, ROBERT M.)
GREER, JANE HARTLEY,)
DAVID L. WALTERS, JOHN E.)
ORR, TRAVIS HARRIS, and)
WAYNE CHANDLER, members of)
the Oklahoma Commission for)
Human Services, all in their indi-)
vidual and official capacities; ALLAN)
OLSON, M.D., MICHAEL P. MOR-)
RIS, M.D., JOHN STUEMKY,)
M.D., CYNTHIA HOUDE-)
SHELDT, M.D., all in their indi-)
vidual capacities; THOMAS PRATT,)
M.D., J. PATRICK LIVINGSTON,)
M.D., W.J. CRAIG, M.D., all in their)
individual capacities; and CHIL-)
DREN'S SHELTER, INC., an)
Oklahoma Corporation,)
)
Defendants.)

FIRST AMENDED COMPLAINT

Plaintiffs, by their attorneys, for their complaint, allege upon information and belief:

1. This is an action for declaratory and injunctive relief against unlawful discrimination at Oklahoma Children's Memorial Hospital and for damages against individuals to compensate for such conduct.

JURISDICTION AND VENUE

2. This is an action under the Civil Rights Acts of 1871 and 1976, 42 U.S.C. §§ 1983, 1985, and 1988 to redress the deprivation under color of statute, ordinance, regulation, custom or usage of the State of Oklahoma of rights secured to the Plaintiffs by the Fourteenth Amendment to the Constitution of the United States, by 42 U.S.C. § 289 1-3 (a), and by the Rehabilitation Act of 1973, 29 U.S.C. § 794. Jurisdiction is conferred on this Court by 28 U.S.C. § 1343(a)(1), (3) & (4), and by 28 U.S.C. § 1331. This Court has pendent jurisdiction of Plaintiffs' state law claims of wrongful death, pursuant to 12 Okla. Stat. Ann. § 1053, and medical malpractice.

3. Venue is properly laid in this district pursuant to 28 U.S.C. § 1391(c).

THE PARTIES

4. Plaintiff Carlton Johnson is a three year old male who was denied beneficial medical treatment at Oklahoma Children's Memorial Hospital.

5. Plaintiff Sharon Johnson is the natural mother of Carlton Johnson.

6. Plaintiffs Frieda Smith and John Smith are the surviving parents of, and on behalf of, Stonewall Jackson Smith, a deceased infant.

7. Plaintiff Cheparney Camp is the surviving parent of, and on behalf of, Melissa Camp, a deceased infant.

8. Plaintiff The Spina Bifida Association of America (SBAA), organized in 1972, seeks to increase public awareness and understanding of Spina Bifida. Spina Bifida is a spinal malformation; myelomeningocele is a type of Spina Bifida. SBAA's membership consists of adults and children with this congenital malformation, their parents, and professionals involved in the care of, or provision of services to, individuals with Spina Bifida. The SBAA conducts national conferences with seminars on scientific, social, medical, and educational matters; it provides support to individuals and families through a network of 106 chapters. SBAA has more than 9,000 members throughout the country. These members will be directly affected by the policies and actions of the Defendants. SBAA has been directly involved in the issue of medical care and treatment for children with other disability rights organizations that co-authored and signed the *Principles of Treatment of Disabled Infants* on November 29, 1983, together with three national medical groups.

9. Plaintiff The Association for Persons with Severe Handicaps (TASH) (formerly the American Association for the Education of the Severely/Profoundly Handicapped) was founded in 1974 to develop, advocate, and implement federal statutes benefiting individuals with severe or profound handicaps. TASH now has more than six thousand members in Oklahoma and throughout the country who include parents, physicians, educators, therapists, and other professionals. TASH members are and will be directly affected by the policies and action of the Defendants. TASH has been directly involved in the issue of medical care and treatment for children with disabilities. *See Legal, Economic, Psychological and Moral Considerations on the Practice of Withholding Treatment from Infants with Congenital Defects* (TASH Monograph #1, 1984). Many of its members provide such care and treatment.

10. Defendant Richard H. Gross, M.D., was a member of the Oklahoma Children's Memorial Hospital myelomeningocele

team, staff of the Department of Orthopaedic Surgery, and consulting physician for Melissa Camp, a deceased infant.

11. Defendant J. Andrew Sullivan, M.D., is the Chief of Pediatric Orthopaedics at Oklahoma Children's Memorial Hospital and a member of the hospital's myelomeningocele team.

12. Defendant David Yngve, M.D., is a member of the Department of Pediatric Orthopaedics at Oklahoma Children's Memorial Hospital and a member of the hospital's myelomeningocele team.

13. Defendant William Barnes, M.D., is a urologist and a member of the Oklahoma Children's Memorial Hospital myelomeningocele team.

14. Defendant Harriet Cousson, M.D., is a pediatrician and a member of the Oklahoma Children's Memorial Hospital myelomeningocele team.

15. Defendant Laura Tull, R.N., is a program coordinator of the Oklahoma Children's Memorial Hospital myelomeningocele team.

16. Defendant Ruth Tatyrek, M.S.W., is a member of the Department of Social Service, Oklahoma Children's Memorial Hospital, and a member of the hospital's myelomeningocele team.

17. Defendant Webb Thompson, M.D., is Chief of Staff and Medical Director at Oklahoma Children's Memorial Hospital, and attending physician to Melissa Camp, a deceased infant.

18. Defendant Daniel Doenity is Administrator of Oklahoma Children's Memorial Hospital.

19. Defendant Jerry D. Razook, M.D., was a member of the Pediatric Cardiology Service at Oklahoma Children's Memorial Hospital. He was an attending physician assigned to care for Stonewall Jackson Smith, a deceased infant.

20. Defendant Gregory Herbeck, M.D., was an intern in the Department of Pediatrics at Oklahoma Children's Memorial

Hospital. He was assigned to care for Stonewall Jackson Smith, a deceased infant.

21. Defendant Antonio Padilla is Chief Executive Officer for Oklahoma Teaching Hospitals.

22. Defendant Robert Fulton is Director of the Oklahoma Department of Human Services, which owns and operates the Oklahoma Teaching Hospitals, including Oklahoma Children's Memorial Hospital.

23. Defendants David L. Walters, Reginald Barnes, W.E. Farhas, Albert Furr, Robert M. Greer, Jane Hartley, John E. Orr, Travis Harris, and Wayne Chandler are the members of the Oklahoma Commission for Human Services, which serves as the governing board for Oklahoma Children's Memorial Hospital. David L. Walters is Chairman of the Commission.

24. Defendant Allan Olson, M.D., is a member of the Oklahoma Children's Memorial Hospital Department of Pediatrics, and was the attending physician for Plaintiff Carlton Johnson during the days immediately following his birth.

25. Defendant Michael P. Morris, M.D., was an intern with the Oklahoma Children's Memorial Hospital Department of Pediatrics and was assigned to care for Plaintiff Carlton Johnson during the days immediately following his birth.

28. John Stuemky, M.D., was an Associate Professor in the Department of Pediatrics between October 17, 1982, and October 20, 1982. He was the attending physician assigned to care for Plaintiff Carlton Johnson during that time.

27. Cynthia Houdesheldt, M.D., was an intern in the Department of Family Practice between October 17, 1982, and October 20, 1982. She was assigned to care for Plaintiff Carlton Johnson.

28. Thomas Pratt, M.D., was an intern in the Department of Pediatrics, Oklahoma Children's Hospital between February 3, 1978, and February 9, 1978, and was a treating physician for Melissa Camp, a deceased infant.

29. J. Patrick Livingston, M.D., was a resident in the Department of Orthopaedic Surgery, Oklahoma Children's Memorial Hospital between February 3, 1978, and February 9, 1978, and was a consulting physician for Melissa Camp, a deceased infant.

30. William J. Craig, M.D., was a treating physician for Melissa Camp, a deceased infant, from February 9, 1978, until her death on May 11, 1978.

31. Children's Shelter, Inc., is an Oklahoma corporation that between 1978 and 1983 provided residential, custodial, and nursing services to Plaintiff Carlton Johnson and to deceased infants Stonewall Jackson Smith and Melissa Camp.

CLASS ALLEGATIONS

32. Plaintiffs bring this action pursuant to Rule 23 of the Federal Rules of Civil Procedure on behalf of all children with myelomeningocele who have been, are, or may in the future be evaluated or treated by the myelomeningocele team or its members at Oklahoma Children's Memorial Hospital and on behalf of their parents and legal guardians. The members of this class are so numerous that joinder of all members is impracticable. There are questions of law and fact involved common to the class, the claims of the Plaintiffs as representative parties are typical of the claims of the class, and the Plaintiffs as representative parties will fairly and adequately protect the interests of the class. The prosecution of separate actions by individual members of the class would create a risk of (a) inconsistent or varying adjudications with respect to individual members of the class which would establish incompatible standards of conduct for the Defendants, and (b) adjudications with respect to individual members of the class which would, as a practical matter, be dispositive of the interests of the other members not parties to the adjudications or substantially impair or impede their ability to protect their interests. Defendants have acted, in all respects stated herein, on grounds generally applicable to the class, thereby making

appropriate final declaratory and injunctive relief with respect to the class as a whole.

FIRST CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 32 as fully set forth herein.

33. Oklahoma Children's Memorial Hospital, one of the Oklahoma Teaching Hospitals, is owned and operated by the State of Oklahoma.

34. The University of Oklahoma is owned and operated by the State of Oklahoma.

35. Defendants are or have been agents, employees, or contractors of the State of Oklahoma or individuals or entities acting in concert with the agents, employees, or contractors of the State of Oklahoma, and act or have acted under color of state law.

36. Defendants directly and actively participated in the discriminatory selection program practiced at Oklahoma Children's Memorial Hospital.

37. Services provided to Plaintiffs at Oklahoma Children's Memorial Hospital receive federal financial assistance, including Medicaid funds, and grants and contracts from the United States Department of Health and Human Services.

38. In October, 1983, an experimental research program of early selection for treatment or nontreatment of infants born with myelomeningocele that took place at Oklahoma Children's Memorial Hospital was described in the medical journal *Pediatrics*. The report encompassed the five year period between 1977 and 1982. Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983).

39. This ongoing research project and related activities began in 1977; it was and is funded in part by federal financial

assistance and by grants and contracts from the United States Department of Health and Human Services.

40. This ongoing research project to which the Plaintiff Carlton Johnson and deceased infants Stonewall Jackson Smith and Melissa Camp have been subjected has not been approved by an Institutional Review Board as required by federal statutes, rules, and regulations.

41. The parents and guardians of the human subjects involved, including Plaintiff Sharon Johnson, mother of Plaintiff Carlton Johnson, Plaintiffs Frieda Smith and John Smith, parents of Stonewall Jackson Smith, deceased infant, and Plaintiff Cheparney Camp, parent of Melissa Camp, deceased infant, were not informed that their infants were participating in experimental research; they have not given their informed consent to their infants' participation.

42. The research project included a selection process applied to infants born with myelomeningocele. A congenital disability, myelomeningocele is charaterized by an opening in the spine at which a "sac" protrudes from the body of the child. This sac contains cerebrospinal fluid and nerve roots that would normally be contained within the spinal column.

43. Beneficial medical treatment of the myelomeningocele consists of prompt surgical closure of the defect, preferably within 48 hours after birth, to prevent meningeal infection.

44. If treated, most children with myelomeningocele will be ambulatory — they may walk with braces or crutches, or may use a wheelchair.

45. Mental retardation is not directly associated with myelomeningocele if it is properly treated; myelomeningocele does not preclude independent existence.

46. Plaintiff Carlton Johnson was born at Oklahoma Memorial Hospital, one of the Oklahoma Teaching Hospitals, on September 12, 1982. He was diagnosed to have myelomeningocele, hydrocephalus, microcephaly, and anemia.

47. Plaintiff Carlton Johnson was transferred to Oklahoma Children's Memorial Hospital approximately twelve hours after his birth.

48. Hydrocephalus, a potenitally serious anomaly often associated with myelomeningocele, occurs when too much cerebrospial fluid accumulates within the crainum. If untreated, this condition causes the head to greatly enlarge and damages the developing brain.

49. Treatment for hydrocephalus normally involves placement of a shunt that drains the excess fluid into another body cavity, most commonly the abdomen.

50. Mental retardation sometimes occurs in infants with hydrocephalus; however, the mere presence of hydrocephalus does not necessarily indicate decreased intellectual capacity, and it does not preclude independent existence.

51. Beneficial medical treatment for Plaintiff Carlton Johnson would have included surgery to close his spinal lesion and placing a shunt to treat his hydrocephalus.

52. The experimental and discriminatory selection process at Oklahoma Children's Memorial Hospital that Plaintiffs Carlton Johnson and deceased infants Stonewall Jackson Smith and Melissa Camp were subjected to was used to determine which infants were to receive "vigorous treatment" — that is, beneficial medical treatment — and which infants were to receive "supportive care" — that is, the denial of beneficial medical treatment predictably leading to the death of the infant.

53. The experimental and discriminatory selection process at Oklahoma Children's Memorial Hospital that Plaintiffs Carlton Johnson and deceased infants Stonewall Jackson Smith and Melissa Camp were subjected to was used to determine which parents or guardians were to receive pessimistic prognoses for their children in order to induce them to follow the myelomeningocele team's recommendation for "supportive care" only.

54. When an infant with myelomeningocele such as Plaintiff Carlton Johnson was presented to Oklahoma Children's Memorial Hospital, a "team" — consisting of a physician's assistant, a pediatrician, an orthopaedist, a neurosurgeon, a urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist — screened the child and the child's family; various diagnostic tests were performed.

55. The myelomeningocele team gave the parents or guardians of infants with high lumbar or thoracic level lesions, severe hydrocephalus, and other associated anomalies a pessimistic evaluation and prognosis based upon the infant's handicaps.

56. If the team's assessment of the degree of the infant's ambulatory potential and the degree of intellectual impairment were pessimistic, then parents or guardians were informed that the team did not regard beneficial treatment to be obligatory. Parents and guardians were not informed that the team did not regard beneficial treatment to be obligatory if the team's assessment of the degree of the infant's ambulatory potential and the degree of intellectual impairment was other than pessimistic.

57. If the child with myelomeningocele was found to have a lower lumbar or sacral lesion and no severe hydrocephalus or if there were no associated anomalies present, then an optimistic prognosis was presented and sac closure was recommended by the team to the parents or guardians to be performed within a few days.

58. If the lesion was at a high lumbar or thoracic level, if severe hydrocephalus or other brain malformations were present and/or if other associated anomalies were noted, then a more formal meeting of the myelomeningocele team was scheduled within 48 hours of admission. The use of these criteria discriminated against Plaintiff infants on the basis of their projected physical and mental disabilities.

59. Infants considered to have a poor prognosis — and who are therefore recommended for non-treatment — have a sur-

vival rate equal to those of infants with a good prognosis — and who are therefore recommended for treatment — if they receive early surgical treatment.

60. The infants who, as a result of the formal team meeting, were denied access to beneficial medical treatment had identical prospects for survival as those infants who were provided with beneficial medical treatment.

61. At the formal team meeting, the myelomeningocele team considered the presence of any one of the following as an indication for nontreatment: (1) thoracolumbar lesion; (2) severe paraplegia; (3) gross enlargement of the head; (4) kyphosis (abnormal curvature of the spine); or (5) other severe congential defects or birth injuries.

62. At the formal team meeting, the myelomeningocele team also considered the presence of the following as indications for treatment or, in their absence, nontreatment: (1) frontal cerebral mantle greater than 1.0 centimeter or brain mass greater than 60% mean for the infants age; (2) absence of a systemic disorder that could cause hydrocephalus and severe brain malfunction; (3) absence of roentgenorgraphic (x-ray) and neurologic signs of severe brain deformity; (4) absence of noteworthy central nervous system bleeding and infection; (5) absence of major malformations that would preclude self-care as an adult; and (6) whether the family had sufficient economic and intellectual resources and lived within reach of an appropriate medical facility, or whether there was a commitment by a social agency to provide needed resources such as a foster home or medical care costs.

63. The myelomeningocele team's determinations were also influenced by a formula — $QL = NE \times (H + S)$. In the formula, QL is quality of life, NE is the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.

64. By considering nonmedical social, economic, and intellectual criteria, as well as the degree of paraplegia, in deter-

mining whether or not to treat these infants, whether or not to recommend treatment, and whether or not to provide parents or guardians with a pessimistic prognosis, the myelomeningocele team discriminated against these infants on the basis of their disabilities and on the basis of socio-economic criteria.

65. It was the myelomeningocele team's policy that external, *i.e.*, nonmedical, circumstances — specifically social, economic, and intellectual criteria, as well as the degree of paraplegia — were crucially important in deciding which infants to treat. Thus, the treatment recommendation for infants with identical medical conditions were sometimes quite different, depending on the nonmedical circumstances of the child and his or her family.

66. Following their evaluation, the myelomeningocele team made a recommendation to the parents or guardians for either "supportive care" or "vigorous treatment".

67. "Vigorous treatment" consisted of prompt sac closure (and thus prevention of infection), the placing of a shunt if hydrocephalus were present, and all other indicated beneficial medical treatment.

68. "Supportive care" consisted of keeping the infant comfortable until death occurred. There was no surgery to close the opening of the infant's back. When hydrocephalus was present, the cerebrospinal fluid was allowed to accumulate causing gross enlargement of the infant's head and compression of the brain. Antibiotics were not given for infection and sedation was not prescribed.

69. Parents or guardians were not informed that nonmedical social and economic factors entered into the recommendation.

70. Parents or guardians were not provided sufficient information to allow them to render voluntary and informed consent to treatment or to nontreatment.

71. Although the myelomeningocele team nominally left the

final decision for either treatment or nontreatment to the parents or guaradian, the members of the myelomeningocele team were the true decisionmakers at Oklahoma Children's Memorial Hospital, not parents or guardian.

72. Medical records of Melissa Camp state that "[t]he parents were informed of the decision not to operate, and were counseled per the decision."

73. Plaintiff Carlton Johnson was evaluated by the myelomeningocele team shortly after his birth. Progress notes made by myelomeningocele team members in Carlton's medical records stated that he was "not a good baby" and that "neurosurgery [was] not enthusiastic about shunting the child and closing the defect."

74. Members of the myelomeningocele team told Plaintiff Sharon Johnson that even with surgery and a shunt Plaintiff Carlton would only live about a year; they recommended nontreatment.

75. The information given Plaintiff Sharon Johnson and on which she based her decision to follow the team's recommendation was unbalanced, incomplete, and inaccurate; she was not given adequate information to make a reasoned and informed decision.

76. Plaintiff Sharon Johnson was intentionally not informed that nonmedical social and economic criteria were considered by the myelomeningocele team in making their recommendation for nontreatment of Plaintiff Carlton Johnson.

77. Once it was determined that Plaintiff Carlton Johnson would be denied access to beneficial medical treatment, he was transferred to the Children's Shelter for custodial care in accordance with procedure of the Defendants to transfer those infants who were deliberately denied beneficial medical care to either Children's Shelter, Inc., or to Bethany Convalescent Home, Inc.

78. Plaintiff Carlton Johnson's medical expenses at

Oklahoma Children's Memorial Hospital and at the Children's Shelter were paid by Medicaid.

79. Defendant Children's Shelter, Inc., deliberately conspired with the myelomeningocele team and its members to withhold, and did withhold, beneficial medical treatment from Plaintiff Carlton Johnson and material information from Plaintiff Sharon Johnson.

80. The children recommended for nontreatment and placed at Children's Shelter and at Bethany Convalescent Home, including Plaintiff Carlton Johnson, were scheduled for and received and continue to receive follow-up care in the out-patient clinics of Oklahoma Children's Memorial Hospital.

81. The health care providers at the out-patient clinic follow the same course of nontreatment initially recommended by the myelomeningocele team.

82. Parents or guardians of infants — including Carlton Johnson, Stonewall Jackson Smith, and Melissa Camp — would have consented to beneficial medical treatment for their infants if they had been provided nondiscriminatorily with balanced, complete and accurate information.

83. By failure to provide parents or guardians with balanced, complete and accurate information, the parents or guardians were effectively deprived of their right to care and custody of their infants and their parent-child relationships were vitiated.

84. The Plaintiff infants recommended for nontreatment were also denied beneficial medical treatment for conditions totally unrelated to their congenital disabilities.

85. Parents or guardians who initially and nominally refused to consent to surgical repair of the myelomeningocele and associated anomolies were not informed that their refusal was deemed by the Defendants to encompass denial of other usual and customary medical treatments for their infants, including the use of appropriate antibiotics and sedation. Until recently,

Plaintiffs did not and could not discover that Defendants had effectively deprived the infants of beneficial medical care and had effectively deprived parents and guardians of the parent-child relationship.

86. On October 17, 1982, Plaintiff Carlton Johnson returned to Oklahoma Children's Memorial Hospital in severe respiratory distress. He also was dehydrated and had an ear infection. Physician's orders issued by Defendants stated there were to be no laboratory tests to monitor his condition; there were to be no intravenous fluids to correct the dehydration; there were to be no antibiotics for his ear infection. If Plaintiff Carlton were to suffer a cardiopulmonary arrest, then he was not to be put on a respirator and no drugs were to be used.

87. A nonhandicapped child or a handicapped child with different social and economic status, or with a different prognosis for intellectual capacity or degree of paraplegia, and with dehydration and severe respiratory distress would have been provided intravenous fluids and antibiotics; he or she would have been resuscitated following cardiopulmonary arrest.

88. Despite this lack of medical care, Plaintiff Carlton did improve and was transferred back to the Defendant Children's Shelter.

89. Surgery to close the lesion and to place a shunt was not performed until January, 1984.

90. As a result of the delay in beneficial medical treatment caused by Defendant's actions, Plaintiff Carlton Johnson's head remains greatly enlarged. In addition, Plaintiff Carlton has incurred substantial physical and mental disabilities and requires constant custodial health care.

91. Plaintiff Carlton Johnson is presently at Bethany Convalescent Center in Bethany, Oklahoma. He remains in the follow-up program of Oklahoma Children's Memorial Hospital and will be referred there for acute care. His expenses continue to be paid by Medicaid.

92. On or about the period of April 16, 1979, through June 7, 1979, at Oklahoma Memorial Hospital, Oklahoma Children's Memorial Hospital, and Children's Shelter, Inc., Defendants negligently rendered or intentionally withheld, medical treatment from Stonewall Jackson Smith, a deceased infant.

93. As a result of the Defendants' actions, as described in paragraph 92, Stonewall Jackson Smith, a deceased infant, suffered great pain of mind and body, and subsequently lost his life.

94. As a result of the Defendants' actions, as described in paragraphs 92 and 93, Plaintiffs Frieda Smith and John Smith lost the companionship, services, and enjoyment of their deceased child, Stonewall Jackson Smith.

95. On or about the period of February 3, 1978, through May 11, 1978, Oklahoma Children's Memorial Hospital, and Children's Shelter, Inc., Defendants negligently rendered medical treatment to Melissa Camp, a deceased infant, or intentionally withheld, medical treatment from Melissa Camp, a deceased infant.

96. As a result of the Defendants' actions, as described in paragraph 95, Melissa Camp, a deceased infant, suffered great pain of mind and body, and subsequently lost her life.

97. As a result of the Defendants' actions, as described in paragraphs 95 and 96, Cheparney Camp lost the companionship, services, and enjoyment of his deceased child, Melissa Camp.

98. Sixty-nine infants with myelomeningocele were seen at Oklahoma Children's Memorial Hospital between 1977 and 1982.

99. Only thirty-six (52%) of these infants were recommended for beneficial medical treatment.

100. The remaining thirty-three (48%) were recommended for nontreatment.

101. Five of the infants recommended for nontreatment by the myelomeningocele team at Oklahoma Children's Memorial Hospital nevertheless received beneficial medical treatment. Three of these children survive.

102. Three other infants recommended for nontreatment received delayed beneficial medical treatment and all three survived.

103. One infant recommended for nontreatment moved out-of-state and was lost to follow-up studies.

104. The remaining twenty-four infants recommended for nontreatment did not receive beneficial medical treatment and died.

105. This experimental and discriminatory selection process which denies infants with disabilities access to beneficial medical care has continued to the present.

106. As a result of the experimental and discriminatory selection process, the Plaintiffs suffered physical, mental, and economic injuries, experienced pain and suffering, and lost rights to care and companionship.

107. This experimental and discriminatory selection process is ongoing; Plaintiffs have no adequate remedy at law.

108. Plaintiffs were and are handicapped individuals as defined by 29 U.S.C. § 706(7)(b), or parents or representatives of such otherwise qualified handicapped individuals.

109. The programs and activities through which the Defendants have provided or denied medical treatment and services to Plaintiffs received and continued to receive federal financial assistance, including Medicaid.

110. Section 504 of the Rehabilitiation Act of 1973 was violated when:

A. Defendants used the anticipated degree of handicap as a basis to recommend that beneficial medical treatment not be provided,

B. Defendants used the anticipated degree of handicap as a basis for providing the parents or guardians with pessimistic prognoses,

C. Defendants determined on the basis of handicap that there was a pessimistic prognosis and then subjected the infants to an evaluation based on nonmedical, socio-economic criteria, and

D. The discriminatory actions of the Defendants caused the parents or guardians to agree to deny their infants beneficial medical treatment.

111. Defendants' conduct as described was and is discrimination solely by reason of handicap which constitutes deprivation of Plaintiffs' rights secured by § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom and usage of unlawful conduct toward the Plaintiffs in violation of § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiff Carlton Johnson, as this Court deems just and equitable against the Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities;

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities.

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

SECOND CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 111 as fully set forth herein.

112. Throughout the period from 1977 to the present, the research project and related activities at Oklahoma Children's Memorial Hospital through which the Defendants provide or deny services and medical treatment to Plaintiffs has been supported in part by grants and contracts from the United States Department of Health and Human Services.

113. The project and related activities as described constituted and continue to constitute research involving human subjects.

114. The Defendants were and are conducting this research project without having submitted a proposal describing it to an Institutional Review Board, in violation of 42 U.S.C. § 289 1-3(a) and 45 C.F.R. § 46.103(b).

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defedants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of 42 U.S.C. § 289 1-3(a), 45 C.F.R. § 46.103(b), and the Civil Rights Act of 1871, 42 U.S.C. § 1983;

and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiff Carlton Johnson, as this Court deems just and equitable against Defedants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities;

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities.

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the court to be equitable and just.

THIRD CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 114 as fully set forth herein.

115. The Defendants involve and have involved Plaintiffs in this research project without first securing the informed consent of their parents or guardians to participate in the research

project in violation of 42 U.S.C. § 289 1-3(a), and 45 C.F.R. §§ 46.116, 46.117, 46.408(b) & 46.408(d).

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defedants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of 42 U.S.C. § 289 1-3(a), 45 C.F.R. § 46.103(b), and the Civil Rights Act of 1871, 42 U.S.C. § 1983; and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson, as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities;

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities;

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorney's fees; and

F. Allow such other additional or alternative relief as may appear to the Court to be equitable and just.

FOURTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 115 as fully set forth herein.

116. Defendants were and are engaged in a conspiracy as described for the purpose of depriving Plaintiffs of the equal protection of 29 U.S.C. § 794, of 45 C.F.R. Part 46, and of the Fourteenth Amendment to the Constitution of the United States.

117. Defendants' conspiracy was and is motivated by an invidiously discriminatory animus against the class of those with disabilities.

118. Defendants' conspiracy has resulted and threatens to result in injury to the persons of Plaintiffs and in depriving them of having and exercising the rights of citizens of the United States indicated in paragraph 115.

119. Defendants' conduct as described violates the Civil Rights Act of 1871, 42 U.S.C. § 1985(3).

WHERFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of 29 U.S.C. § 794, 45 C.F.R. Part 46, the fourteenth Amendment to the constitution of the United States, and § 1985(3) of the Civil Rights Act of 1871, 42 U.S.C. § 1985(3) and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson, as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities.

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities;

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daugher, Melissa Camp, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

FIFTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 119 as fully set forth herein.

120. Defendants' conduct as described constituted and continues to constitute state deprivation of life and liberty without due process of law and without procedural due process safeguards and thus deprivation of Plaintiffs' rights secured by the Fourteenth Amendment to the Constitution of the United States.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of the Fourteenth Amendment to the

Constitution of the United States, and the Civil Rights Act of 1871, 42 U.S.C. §1983; and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson, as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities.

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities;

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

SIXTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 120 as fully set forth herein.

121. Defendants' conduct as described constituted and con-

tinues to constitute state deprivation of life and liberty without due process of law, violating the substantive due process fundamental rights of life and liberty, and thus deprivation of Plaintiffs' rights secured by the Fourteenth Amendment to the Constitution of the United States.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of the Fourteenth Amendment to the Constitution of the United States, and the Civil Rights Act of 1871, 42 U.S.C. § 1983; and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson, as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities.

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities;

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

SEVENTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 121 as fully set forth herein.

122. Defendants' conduct as described constituted and continues to constitute state deprivation of life and liberty without due process of law, violating the substantive due process fundamental right of parents to the care and custody of their children, and to information concerning their children, and thus deprivation of Plaintiff's rights secured by the Fourteenth Amendment to the Constitution of the United States.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom and usage of unlawful conduct toward the Plaintiffs in violation of the Fourteenth Amendment to the Constitution of the United States, and the Civil Rights Act of 1871, 42 U.S.C. §1983, and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson, as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities.

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D.,

Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities;

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

EIGHTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 122 as fully set forth herein.

123. Defendants' conduct as described constituted and continues to constitute state deprivation of equal protection of the laws, and thus deprivation of Plaintiffs' rights secured by the Fourteenth Amendment to the Constitution of the United States.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Find and declare that the Defendants have engaged in a policy, practice, custom, and usage of unlawful conduct toward the Plaintiffs in violation of the Fourteenth Amendment to the Constitution of the United States, and the Civil Rights Act of 1871, 42 U.S.C. § 1983, and to forever enjoin Defendants, their agents, successors, and employees from engaging in such conduct.

B. Render such judgment of damages on behalf of Plaintiffs Carlton Johnson and Sharon Johnson as this Court deems just and equitable against Defendants Allan Olson, M.D., Michael

Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities.

C. Render such judgment of damages on behalf of Plaintiffs Frieda Smith and John Smith for the death of their son, Stonewall Jackson Smith, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Stonewall Jackson Smith as the Court deems just and equitable against Defendants Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in their individual capacities.

D. Render such judgment of damages on behalf of Plaintiff Cheparney Camp for the death of his daughter, Melissa Camp, for the destruction of the parent-child relationship, and for grief and loss of companionship resulting from the death of Melissa Camp as the Court deems just and equitable against Defendants Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in their individual capacities.

E. Allow Plaintiffs their costs herein and reasonable attorneys' fees; and

F. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

NINTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 123 as fully set forth herein.

124. Defendants' conduct as described failed to meet the accepted standard of medical care, rendering Defendants liable for damages to Plaintiff Carlton Johnson.

125. As a result of Defendants' conduct as described in paragraph 124, Defendants have caused Plaintiff Carlton Johnson actual damages in the amount of $8,000,000.00.

126. Plaintiffs further allege that Plaintiff Carlton Johnson is entitled to recover punitive damages in the amount of $10,000,000.00.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Render Plaintiff Carlton Johnson, by and through his next friend Sharon Johnson, actual damages against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities in the amount of $8,000,000.00;

B. Render Plaintiff Carlton Johnson, by and through his next friend Sharon Johnson, punitive damages against Defendants Allan Olson, M.D., Michael Morris, M.D., John Stuemky, M.D., and Cynthia Houdesheldt, M.D., in their individual capacities in the amount of $10,000,000.00.

C. Allow Plaintiff Carlton Johnson, by and through his next friend Sharon Johnson, his costs herein and reasonable attorneys' fees; and

D. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

TENTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraphs 1 through 126 as fully set forth herein.

127. Defendants' conduct, as described in paragraphs 92 to 94 with respect to Stonewall Jackson Smith, a deceased infant, failed to meet the accepted standard of medical care pursuant to 12 Okla. Stat. Ann. § 1054, rendering Defendants liable for damages.

128. As a result of Defendants' conduct as described in paragraph 127, Defendants have caused actual damages in the amount of $2,000,000.00.

129. Plaintiffs further allege that Frieda and John Smith, surviving parents of Stonewall Jackson Smith, deceased infant,

are entitled to recover punitive damages in the amount of $10,000,000.00.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Render Plaintiffs Frieda Smith, and John Smith for the death of Stonewall Jackson Smith, actual damages against Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in the amount of $2,000,000.00.

B. Render Plaintiffs Frieda Smith and John Smith, for the death of Stonewall Jackson Smith, punitive damages against Jerry D. Razook, M.D., Gregory Herbeck, M.D., and John Stuemky, M.D., in the amount of $10,000,000.00.

C. Allow Plaintiff Frieda Smith and John Smith their costs herein and reasonable attorneys' fees; and

D. Allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

ELEVENTH CAUSE OF ACTION

Plaintiffs incorporate by reference all allegations contained in paragraph 1 through 129 as fully set forth herein.

130. Defendants' conduct, as described in paragraph 95 to 97 with respect to Melissa Camp, failed to meet the accepted standard of medical care pursuant to 12 Okla. Stat. Ann. § 1054, rendering Defendants liable for damages.

131. As a result of Defendants' conduct as described in paragraph 130, Defendants have caused actual damages in the amount of $2,000,000.00, respectively.

132. Plaintiffs further allege that Plaintiff Cheparney Camp, surviving parent of Melissa Camp is entitled to recover punitive damages in the amount of $10,000,000.00.

WHEREFORE, Plaintiffs respectfully pray this Court to:

A. Render Plaintiff Cheparney Camp, for the death of Melissa Camp, actual damages against Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick

Livingston, M.D., and William Craig, M.D., in the amount of $2,000,000.00.

B. Render Plaintiff Cheparney Camp, for the death of Melissa Camp, punitive damages against Richard H. Gross, M.D., Webb Thompson, M.D., Thomas Pratt, M.D., J. Patrick Livingston, M.D., and William Craig, M.D., in the amount of $10,000,000.00.

C. Allow Plaintiff Cheparney Camp his costs herein and reasonable attorneys' fees; and

D. allow such other, additional, or alternative relief as may appear to the Court to be equitable and just.

Respectfully submitted,

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*For Causes of Action One through Eight only.

Early Management and Decision Making for the Treatment of Myelomeningocele

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ABSTRACT. A program for early selection and treatment of the infant with myelomeningocele was developed at the University of Oklahoma Health Sciences Center in 1977. Over a 5-year period, 69 babies were evaluated, 36 babies were recommended for early vigorous treatment. Of the 33 babies for whom only supportive care was recommended, five were initially treated at the parents' request, two underwent delayed vigorous treatment, one was subsequently treated by "crisis management," one moved and did not return for follow-up, and 24 received only supportive care. All 24 babies died between 1 to 189 days of age (mean 37 days). The involvement of several physicians and paramedical support personnel is considered essential for this approach of early selection and treatment. Continued support and regular follow-up is necessary for any baby who receives only supportive care. Parents retain legal custody. Although ethical concerns make any approach difficult, the method presented is considered to be the best alternative available at this time. *Pediatrics* 1983;72:450—458; *myelomeningocele.*

Prior to 1960, the large majority of children born with myelomeningocele died in infancy. Neurology textbooks of that era are blatantly pessimistic in their description:

> The presence of a sac, however, justifies an unfavorable prognosis where death usually occurs in infancy.[1]
>
> Most patients with meningomyelocele succumb in infancy; a few survive, only to die later.[2]

In the past two decades an incredible change has occurred in the management of the problems associated with the birth of an infant with myelomeningocele. From the time when the diag-

nosis was commonly felt to be synonymous with early death, the pendulum swung to a vigorous treatment approach advocated by a group in Sheffield, England.[3] They advocated early closure of the sac on an emergent basis for all newborns with myelomeningocele, and shunting for hydrocephalus when necessary. During childhood, multiple orthopaedic procedures and urologic diversion were often performed.[4] In 1971, John Lorber,[5] the group's pediatrician, presented an analysis of 524 patients thus treated, and he concluded that a better quality of life would result if a process of selection had been performed at birth. Some of his colleagues did not share his opinions.[6] In the same year, Smith and Smith[7] outlined the selection program for infants with myelomeningocele that had been developed at the Royal Children's Hospital in Melbourne, Australia. This program deferred sac closure for infants with high level lesions, a practice not generally accepted at the time as delay was felt to jeopardize remaining neurologic function. If the child thrived despite withholding early surgery, the situation was reassessed and active treatment commenced.

In 1973, Lorber[8] reported on 37 babies subjected to the screening criteria he had developed. If the child had any one or a combination of the following, the baby would not receive active treatment but only supportive nursing care: (1) thoracolumbar lesion; (2) severe paraplegia; (3) gross enlargement of the head; (4) kyphosis; and/or (5) other severe congenital defects or birth injuries. Of the 37 babies studied, 25 had findings fulfilling one or more of these criteria, and thus they were expected to have a poor prognosis for quality of life. These 25 were untreated, and all died within 9 months. This experience was updated in 1981,[9] at which time these original 37 babies were included in a series of 120 infants evaluated from 1971 to 1976. Among 71 infants not treated, all died; 90% died within 6 months. Lorber and Salfield[9] reported a high degree of parental satisfaction with their program, and increased usage of their services by referring pediatricians during the period studied.

In the United States, in 1974, Shurtleff et al[10] presented a carefully documented work on the fate of 371 patients with myelodysplasia, including 88 patients who had been treated only with supportive care. Criteria for Shurtleff's group differed from Lorber's in that aggressive treatment was recommended for any infant, regardless of the level of the lesion, if a good intellectual prognosis was noted. Therefore, if all the following specific criteria were satisfied, maximum treatment was undertaken: (1) frontal cerebral mantle greater than 1.0 cm or brain mass greater than 60% mean for age; (2) absence of a systemic disorder that could cause hydrocephalus and severe brain malfunction; (3) absence of roentgenographic and neurologic signs of severe brain deformity; (4) absence of noteworthy CNS bleeding and infection; (5) absence of major malformations that would preclude self-care as an adult; and (6) a family with economic and intellectual resources who lived within reach of an appropriate medical facility, or a commitment by a social agency to provide needed resources such as a foster home or medical care costs. Shurtleff et al emphasized a complete discussion with the family as a part of the process. Of the 88 patients treated with supportive care, only 52 were born before 1965 (early group). In 1965, an evaluative process of the newborn was begun, and 36 of the 88 were selected for only supportive treatment after that time (younger group). All 34 patients of the latter group whose families accepted the initial recommendation of nonintervention were treated in nursing homes. Of the early group, 30% survived to the second decade and 10% of the younger group survived to the second year of life, demonstrating that some babies survived in spite of a dismal initial evaluation.

The fate of the untreated infant has been the primary source of discomfiture in the debate over the treatment of the newborn with myelomeningocele. Freeman, reflecting on the presence of unexpected survivors,[11,12] stated that because active euthanasia of these infants is not acceptable, treatment of all affected infants is the preferred course.[13] Stein et al[14] discussed plans for a selective process but stated in their discus-

sion, "the fact that most of the children die should provide solace to no one. We cannot condone the opinion that this high mortality among untreated patients justifies a lack of therapeutic effort." Whereas a working party in England[15] achieved a consensus on the ethics of selective treatment of spina bifida, policies in the United States tended to be unstated and varied, and certainly more conservative. John Fletcher[16] described the atmosphere in this country: "There has not been a concerted attempt to refine criteria for nontreatment in the United States, probably due to the extraordinary ethical pluralism that obtains, as well as the precarious legal situation." A documented selection process has been employed in several centers in the United States with varying results. Woolraich,[17] from Iowa, reported on the evaluation of 27 babies over a 3-year period. Of these babies, 12 fulfilled Lorber's criteria as not qualifying for vigorous treatment. Four families nevertheless opted for vigorous treatment; two babies of these four died within 7 months. Of the remaining eight infants, three were subsequently treated and five died. The age at the time of death is not delineated. Another study from Children's Hospital at Michigan[18] noted that 31 of 75 newborns were initially not treated, but 70% of these 31 babies were still alive at 18 months. A major difficulty of this program was the inability of the physician team and other health care personnel to adhere to the protocol, along with the group's fear of litigation and a possible change in referral patterns. The "precarious legal situation" described by Fletcher[16] has been well outlined by Robertson and Fost.[19,20] Although Taub's analysis[21] of the same subject has less rigid conclusions, the potential for legal problems for physicians, nurses, and parents is certainly present. Recently,[22] the issue has met with political input from the Department of Health and Human Services which has warned hospitals across the country that they risk losing federal funds if treatment is withheld from babies born with birth defects.

With this background into others' experiences, it seems worthwhile to report our selection process at the University of Oklahoma Health Sciences Center in the treatment of the

infant with myelomeningocele. Our program is based on the following premises: (1) neurologic status will not deteriorate following nonoperative management in the newborn, therefore there is no urgency for immediate operation[23,24]; and (2) "The conclusive justification for selection in the spina bifida cases appears to be the documented suffering that is not only reduced but prevented, if one is persuaded that death is preferable to life under certain circumstances . . . it is prima facie irresponsible to obtain knowledge about the results of surgery on high risk infants and then not to use the negative results in informing the parents and others of the consequences of surgery."[16]

METHOD

The philosophy of the myelomeningocele team in evaluating the newborn at the University of Oklahoma Health Sciences Center (OUHSC) is similar to that expressed by Cohen[25]:

> My feeling is that these children and their families should be evaluated by a team, including at least a pediatrician, an orthopaedist, urologist, neurosurgeon, and a social worker. After a careful appraisal of all factors, a tentative prognosis should be made and one of the team members, acting as a coordinator should interpret the findings and prognosis to the parents while the others should be available for whatever specific help they can provide to the parents. The social worker should be involved in the discussion to be aware of what the parents are told; he can then interpret information, which can be confusing, and can continue to provide emotional support to them. On the basis of the prognosis and the outline of therapy that may be found to be necessary, the physician should assist the family as to what treatment is to be carried out. Whatever decision the parents make, it is important that they be relieved of any sense of guilt.

The myelomeningocele team at OUHSC consists of a physician's assistant, acting as a full-time program coordinator, a

pediatrician, an orthopaedist, a neurosurgeon, a urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist. One of the physicians acts as chief of the program. When a newborn with myelomeningocele is admitted, the coordinator contacts the physicians, nurse, and social worker. All services are to assess the status of the baby within 24 to 48 hours of admission. Radiographs of the skull and spine, and a computed tomographic (CT) scan of the head are performed. At the time of admission, the family is given general information about myelomeningocele, and informed that a complete evaluation will be performed before specific recommendations can be made. If the child is found to have a lower lumbar or sacral lesion and no severe hydrocephalus or if there are no associated anomalies present, sac closure is recommended within a few days. If the lesion is at a high lumbar or thoracic level, severe hydrocephalus or other brain malformation is present, and/or other associated anomalies are noted, a more formal meeting of the team is scheduled within 48 hours of admission. Whereas there are no specific criteria for treatment, factors considered significant by Shurtleff et al[10] (and to a lesser extent those considered significant by Lorber[8]) are reviewed. Usually a consensus is achieved, but sometimes the team is ambivalent. In this instance, a recommendation for treatment is made. At this point, one physician accompanied by the coordinator, social worker, and/or nurse meets with the family to discuss the recommendations of the team. The prognosis regarding ambulatory potential can be offered in fairly specific terms, but opinions regarding intelligence or retardation are given in more general terms. If the team's assessment is pessimistic, the family is informed that we do not consider them obligated to have the baby treated. They are given time to assess the information before they reach a decision. Occasionally several meetings are held with the family. Other members of the team are available for consultation if requested. If the mother of the infant is in another hospital in the Oklahoma City area, a physician and the coordinator and/or social worker will visit her at that site. They then relay the

feelings and recommendations of the team. If a pessimistic evaluation and prognosis has been offered the family but they still wish treatment, their wishes are followed unless the operative risk is considered a direct threat to the baby's life. (The reverse situation, refusal to consent to recommended surgery, did not occur).

If the family elects to defer surgery, they are given the option of having the child placed in a children's shelter, which is an intermediate nursing facility caring for young children. Legal custody remains with the parents. The baby is scheduled for regular follow-up in the myelomeningocele clinic until death or until a decision to treat the child more aggressively is made. Antibiotics are not given for infection and sedation is not prescribed. Regular contact with the family is maintained by the clinic coordinator and social worker.

RESULTS

During the period July 1, 1977 through June 30, 1982, 69 babies with myelomeningocele were evaluated. Vigorous treatment was recommended for 36 babies (52%) (Table 1) and supportive care was recommended for 33 babies (48%) (Table 2). Of the 36 babies receiving vigorous treatment, 35 are still alive; one child died at 14 months in a motor vehicle accident. Only supportive care was recommended for 33 babies, and 28 families accepted this approach. Only two of these 28 babies went home with their parents, the other 26 babies were cared for at the children's shelter. The other five families requested early vigorous treatment. Two of these five babies died at 9 and 72 days of age, respectively; the other three are alive and well. One family moved to California when their baby was 1 month of age and is lost to follow-up. Three babies had delayed treatment. One child, who lived with his family, received a shunt for massive hydrocephalus at 4 months of age and essentially has had "crisis management" since that time (see "Discussion"). The other babies were placed in the children's shelter initially and were routinely followed in the myelomeningocele clinic. At age 6 months, one baby was noted to be robust and thriving and

a decision for vigorous treatment was made by the family at that time. The child is now 3 years old and lives at home with his family. The other baby commenced treatment at 1 month of age at the parents' request. The treatment and present status of the 33 babies for whom no treatment was initially recommended are schematically presented in the Figure.

All 24 babies who continued to receive only supportive care have died. These babies did not receive active treatment for infection and other acute illnesses. Sedatives were not routinely administered. The age at death has ranged from 1 to 189 days, with a mean of 37 days and a median of 25 days.

TABLE 1. Neurologic Levels of Treated Babies (N = 36)

Level	Male	Female
T-10 and above	1	1
T-11 to L-1	2	4
L2-4	5	10
L-5 to sacral	8	5
Totals	16	20

TABLE 2. Neurologic Levels of Babies Who Received Supportive Care

Level	Total for Whom No Treatment Initially Recommended (N = 33)*		Treated at Parents' Request (N = 8)		Supportive Care Only (N = 24)	
	Male	Female	Male	Female	Male	Female
T-10 and above	9	7	4	0	5	6
T-11 to L-1	4	5	2	0	2	5
L-2-4	3	0	0	0	3	0
L-5 to sacral	3	2	1	1	2	1
Totals	19	14	7	1	12	12

* Includes one female infant with thoracolumbar neurologic level who was untreated at 1 month of age and who moved out of state and was lost to follow-up.

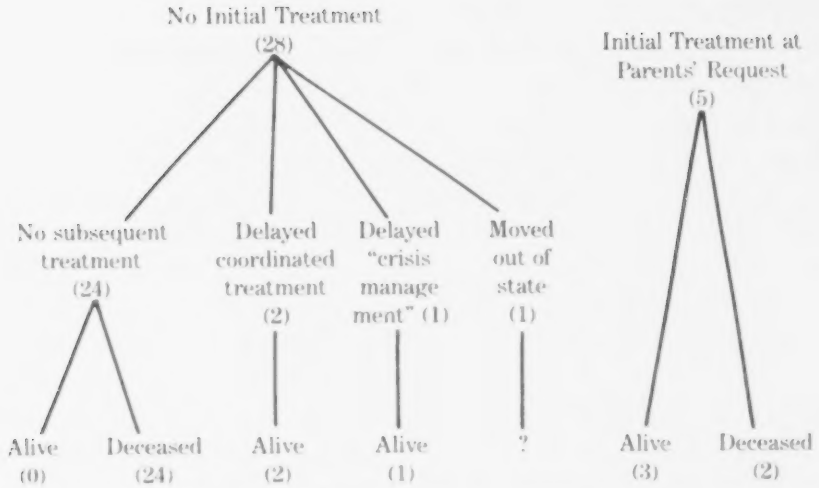

Figure. Babies for whom no treatment initially recommended (N = 36). Number of infants is shown in parentheses.

DISCUSSION

Two basic questions appropriate for assessing a program for the treatment of the newborn with myelomeningocele are: (1) Is the program workable? (2) Does it address, in a reasonable fashion, the present ethical dilemma surrounding this issue?

In considering the first question, "team" approaches do present problems in treatment and function. This was aptly demonstrated by the report from Children's Hospital of Michigan,[18] which listed noncompliance by the team as a major problem. One solution is a dominant team leader; but a major difficulty with this arrangement is the fact that the team leader may not always be present for every decision. Several physician members of our team have functioned as the primary physician contact with the family. The clinic coordinator, nurse, and social worker all serve as an accessible support system. We feel that the availability of several team members with the capability of filling a primary role is essential in ensuring that the selection process will not fail due to the absence of a certain key individual. The pediatrician, orthopaedist, and neurosurgeon have all functioned as the primary contact physi-

cian. We would emphasize that any physician experienced in the long-term multidisciplinary care of myelomeningocele can acquire sufficient general expertise, in addition to his particular specialty expertise, to offer worthwhile and accurate information to the family. The acquisition of such general expertise requires frequent communications among team members. The availability of paramedical team members to the family during the decision-making period is crucial; families have relied extensively on various team members during this stressful period.

CASE REPORTS

Case 1

A female infant was noted to have severe congenital hydrocephalus and an L-1 level of paralysis at birth. A recommendation against vigorous treatment was offered to the parents. The family, especially the father, visited at length with the paramedical team members during the first week and made three visits to the children's shelter before deciding against active treatment. While the baby was alive, the parents brought her for follow-up to the myelomeningocele clinic and to the emergency room when she was ill. The parents maintained custody but day-to-day care was rendered by the children's shelter. The infant died at 88 days. The family expressed appreciation that all information was available to them before definitive treatment was undertaken, and they were subsequently comfortable with their decision. They felt vigorous, long-term care of this baby would have added undue stress to their family unit.

Problems have lessened as the evaluation process has matured. A most valuable development in our program was formulating the policy whereby a particular physician would not give definite recommendations to the family at the time of the initial visit. This policy has greatly diminished the instances in which the family received different information

from different consultants — a most frustrating experience for the parents. Occasionally, a decision was made in what could be considered, in retrospect, an inadequate assessment.

Case 2

A boy now 5 years of age from a small town in rural Oklahoma was transferred via ambulance shortly after birth, accompanied by his father. He was noted to have congenital hydrocephalus and a large thoracolumbar sac. A rapid evaluation was made. Only two of the team members saw the baby, and no input from Social Services was obtained. The child was discharged to his home 24 hours later with a recommendation against treatment. The parents took meticulous care of him and sought a second opinion in a neighboring state at 3 weeks of age. This consultant concurred with the recommendation against treatment. At 4 months of age, a ventriculoperitoneal shunt was inserted, due to a rapidly enlarging head size. The baby has had multiple admissions since that time at both Oklahoma Children's Memorial Hospital and the family's local hospital for recurrent shunt problems and multiple lower respiratory tract infections, which have been vigorously treated. At the present time, the boy rolls over, but does not sit. The parents acknowledge that the care of this child has been stressful, but they feel that they have a strong marriage and are coping well. They also feel that the baby's hydrocephalus should have received earlier treatment. The family presently has financial difficulties and has been sued by the local hospital for nonpayment of bills.

Comment. This family was unable to care for their baby at home without giving active vigorous treatment. Had a more complete and careful evaluation been performed, including an evaluation from Social Services, this could have been known prior to discharge. Athough the family has coped well, their role would probably have been easier had a more definite plan of treatment been instituted at

the time of birth. Although the boy has received treatment, it has always been "crisis oriented" and cannot be regarded as optimum treatment.

It may be argued that the lack of immediate specific information and recommendations for treatment increases anxiety among parents. However, our impression is that if the family is informed that myelomeningocele is a complex condition requiring complete evaluation before definitive treatment is recommended, and if a member of the team is readily accessible, better understanding and rapport is developed between parents and staff than with "emergent" surgery.

The "luxury" of having several days or more to arrive at a consensus decision necessarily repudiates the concept that immediate sac closure is necessary to deter further neurologic damage. Although this approach has been recommended in the strongest of terms,[3] Boston and Wilkinson[24] have inferred that better results may be obtained from a delay in sac closure. Periodic follow-up of babies who do not have surgery affords an opportunity for a change in treatment, as both Smith and Smith[7] and Gurney and McCarthy have demonstrated.[26] Of 132 babies selected for nontreatment in the latter program, 33 had that decision reversed between 40 days and 16 months. The 13 survivors of these 132 babies selected originally for nontreatment were studied for mobility, intelligence, and continence; they were found to be similar to a group of maximally treated patients with comparable neurologic status. The authors concluded that the survivors of the group selected for nontreatment had fared as well as those who had the "benefit" of total care. The pertinent point is that immediate sac closure does not appear mandatory, and thus, allows time for thoughtful decisions.

The "untreated survivor" has not been a significant problem in our experience. All 24 babies who have not been treated at all have died at an average of 37 days. These data indicate to us that we are able to select babies with a more positive outlook — the only nonsurvivor of 36 babies for whom vigorous treatment

was recommended died as a result of a motor vehicle accident. Four of the six babies for whom nontreatment was suggested but was rejected by the parents are still alive, as are two infants treated "late." Treatment of these children is identical with that given to those "selected" for treatment.

We conclude that this program is workable and that a reasonably accurate assessment may be made at the time of birth. With the number of diverse personnel involved, differences do occur in decision making and the approach is not uniform from one case to the next. However, the alternatives of a dogmatic protocol or an incomplete evaluation by less than all services involved appeared to us to be unsatisfactory choices.

Some may wonder about the ability of the family and team to continue the relationship if an opinion against active treatment was offered the family and they declined this approach. In fact, all five families with surviving children in this category continued to receive care from our clinic.

Case 3

A male infant was noted to have a T-10 level of paralysis and congenital hydrocephalus at birth. A pessimistic outlook was given to the parents, but they were firm in their insistence that vigorous treatment be undertaken. The child is now 3 years old and ambulates short distances with extensive orthotic support. The parents were influenced by a cousin who also had myelomeningocele and hydrocephalus and was not treated. The cousin lived until age 7 years with massive hydrocephalus; this possibility was unacceptable to the parents. They have expressed appreciation that they can differ with recommendations of the team and yet still feel comfortable in returning for care. Their only resentment of the initial hospitalization occurred when two physicians apparently reminded the parents of the baby's poor prognosis after sac closure had been performed. The parents have not seen these physicians again as they were presumably housestaff who

rotated through services involved in the treatment procedure at that time. Although content with the decision of having their child vigorously treated, the mother felt she would not have been able to give the child this type of care and attention if she were a single parent or if she was required to work for financial reasons.

Comment. Both family and team must be capable of accepting some subjectivity in the evaluative process and retain some flexibility. This relationship has not been impaired by "noncompliance." An element of mutual trust is essential between the family and the team if a positive relationship is to be maintained.

The second question, concerned with the ethical dilemmas surrounding this issue, has many facets. Perhaps the best way to address the problem is by asking who should make the decision about treatment and upon what data base? The opposing sides of the first part of the questions have been eloquently described in detail in the ongoing debate between Duff and Campbell[27-29] and Fost.[30,31] Duff and Campbell argue that the concerned family and physician are best equipped to make these difficult decisions without outside intervention. They regard the vigorous nonselective approach to save life, the attitude of "doing the most we can for the patient," as a "disease-oriented" approach that can be harmful to families who make the painful but wise decision for death when considering the fate of their defective newborn. Duff and Campbell criticize efforts made to intimidate parents into agreeing to treatment by questioning the parents' motives or fitness as parents in not trying to protect their baby's life. Such statements as "Since the prognosis is a little uncertain, we must always treat," and "treating is always right," unfairly muddle the issue for the family.[28] Duff feels[29] that troubled families can assimilate information, use their resources (extended family, church, etc.) and make sound decisions, including the occasional decision for death. Ackerman[32] follows this reasoning even further, stating that a commitment by the parents to care for and nurture their

afflicted child should be the primary factor in such decision making.

Fost[30] argues that parents may not be suitable proxies for the child. Parents may underestimate the capacity for pleasure they would obtain from rearing a child with a birth defect or handicap, they may see their child's continued interests as being a threat to their own well-being, or they may be emotionally unable to assimilate the information given them. Fost[31] advocates outside viewpoints, including the courts, to arbitrate decisions in which the parents might not be acting in the best interest of the child. An intermediate approach, although more inclined toward the views of Duff and Campbell, is that of McLaughlin and Shurtleff.[33] They defer decision making to the wishes of the parents after extensive counseling, except on rare occasions when they feel a strong case exists for aggresive treatment and the parents do not concur. We have attempted to follow this approach although, to this point, have had no reason to convince parents or request court action. McLaughlin and Shurtleff[33] succinctly summarized the process:

> One must be acutely aware of one's own biases, the background and attitudes of the family, the legal and social elements, and yet somehow make decisions that are primarily in the best interest of the infant.

We have also been influenced by Shaw's formulation[34] of the quality of life. In this formula, $QL = NE \times (H + S)$, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society. Although Ramsey[35] vigorously discounts any consideration for quality of life arguments, there is no evading the fact that external circumstances are crucially important in the outlook for the newborn with myelomeningocele. Thus, the treatment for babies with identical "selection criteria" could be quite different, depending on the contribution from home and society. Veatch[36] has criticized the use of technical criteria as subjective and criticizes "medicalizing value choices . . . even if there were

complete agreement about diagnosis and prognosis of a seriously affected spina bifida infant, there would be only slightly more argument about what we ought to do in a particular case." Shaw's formula recognizes this subjectivity and uncertainty, and makes the contribution of not ignoring it.

Considering the societal component of this formula is felt by some to be an inappropriate procedure or merely mentioned in passing as something that ought to be done. One cannot be involved in the long-term care of myelomeningocele, however, without becoming aware of the increased stress these families undergo in raising their families.[37] We feel that at the present time society is given a schizophrenic message to the families of patients with defective newborns. On the other hand, groups supporting sanctity of life are insisting that all such babies be saved, and the federal government has recently adopted this stance by threatening the withholding of funds from hospitals in which such babies might be allowed to die.[22] Parents are also informed that under Public Law 94-142, children have a right to an appropriate education tailored to individual needs.[38] On the other hand, support for funding to finance medical needs is diminishing with attempts to cut government spending,[39] and schools are struggling to provide the increased personnel necessary to comply with PL 94-142 as their budgets tighten.[40] It is becoming easier to visualize a cruel irony in which maximum treatment would be mandated for newborns with myelomeningocele, but funding for their nurture later in childhood is unavailable. This would, in effect, be a delayed triage with no criteria except the availability of financing. Hopefully, policymakers can avert this scenario, but we feel that the trend is developing.

The disposition of babies for whom only supportive care is recommended is of extreme importance. The vast majority of such patients in this study were cared for in an intermediate care nursing facility after transfer from the acute care hospital at approximately 1 week of age. Legal custody remains with the parents. The day-to-day nurturing of such patients is

stressful for the personnel involved; however, we feel that it has been rendered with care and compassion at the facility utilized for these babies. For new acute problems, the babies are referred back to Oklahoma Children's Memorial Hospital, usually (but not always) ensuring adherence to protocol. No sedatives were given, refuting the (not very subtle) allegations of Zachary[6] that babies selected for only supportive care do not die spontaneously. The cause of death of most babies in this study is uncertain as autopsy was infrequently performed. Clinically, it is often difficult to ascertain the cause of death; however, some possible causes may be respiratory tract difficulties secondary to brain dysfunction combined with an acute infectious process.

If, as McLaughlin and Shurtleff have maintained, "one must be acutely aware of one's own biases,"[33] some explanation of our bias is in order. We would describe our approach as being aligned with that expressed by McCormick,[41] a Jesuit priest, who noted the difficulty in objectively evaluating the prognosis for a meaningful life in the newborn. He feels the best we can do under the present circumstances is to apply "broad guidelines . . . a guideline is not a slide rule that makes a decision. It is far less than that . . . it is more like a light in a room, a light that allows the individual object to be seen in the fullness of their context."[41] He feels that we must face the responsibility that the sophistication of modern medical technology has given us, a technology not present 30 years before when most of these babies would have died with little attention. McCormick describes life as a basic and precious good, but only a relative good. It is not to be sustained in the face of extraordinary hardships; these hardships can include physical, geographic, and financial considerations. His primary guideline in decision making is the potential of the patient for human relationships. If the struggle to survive requires extraordinary hardships, which are not specifically defined, and are recognized as relative, the baby may be allowed to die. He cautions that mistakes will be made, therefore, we must, in times of doubt, always lean toward the side of life.

SUMMARY

We have attempted to utilize the resources available to us and to all multidisciplinary teams — several physicians familiar with the long-term outlook of these children and paramedical support personnel. This makes available a pool of physicians and paramedical personnel, any of whom can serve as a primary contact for the family while systematic evaluation of the newborn is performed. This process affords the flexibility necessary to assess each baby and family on an individual basis. We do not feel that a surgeon involved with the initital care who will not maintain follow-up of the child throughout growth should have a role in counseling and decision making on an emergent basis for a newborn with myelomeningocele, nor do we feel that there is any place at present for sac closure on an emergent basis and then referring the child after acute treatment to a multidisciplinary team. With the perspective gleaned from the long-term care of these children, even without hard "criteria," valuable and pertinent information can be gathered within a few days after birth to make a reasoned decision — a decision that considers the perspective of both baby and family. Although one can never feel comfortable with such dilemmas, this approach seems to us the best alternative available at this time.

The "ethical pluralism and precarious legal situation that obtains" will be unchanged until those involved with the delivery of care to newborns with myelomeningocele define their own process. When this happens, perhaps a more fruitful and productive interaction will result between health care personnel and institutions on the one hand and legal and governmental agencies on the other.[42] All personnel, agencies, and institutions influence the future of the baby with myelomeningocele in presently unpredictable ways, and this in itself renders the decision-making process more difficult. Each center involved with these dilemmas has the capability of assessing its own process and delineating what factors are weighed. Defining these factors would seem the logical first

step in untangling the uncertainty that shrouds this entire problem at the present time.

ACKNOWLEDGEMENTS

The authors thank Drs. Ralph Kaplan and James Rogers for providing neurosurgical care to these children; Jane Grougan, PAC, who was instrumental in the initiation of this program; Sook Marino, Susan Cook, Tonya Giessman, and Laura Tull who have provided primary care for the families involved in this study; and Susan Istre and Mary Stranger who provided nursing care.

Note Added in Proof. This year, government policies have become even more controversial with initiation of the "hot line" by the same Department whereby anyone questioning the care of a newborn could report to a governmental agency. Although notices to this effect have been removed from nurseries by court order, the issue has not been resolved at the time of writing. The President's Commission for the Study of Ethical Problems in Medicine has concluded that "Primary responsibility for ensuring that morally justified processes of decision-making are followed lies with the physician" and that decisions in treatment for seriously ill newborn babies should be made by their parents unless they are incapable of deciding, are unable to agree, or have made a decision that is "clearly against the infant's best interests."[43]

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IN THE
UNITED STATES DISTRICT COURT
FOR THE
WESTERN DISTRICT OF OKLAHOMA

CARLTON JOHNSON, et al.,	)	
	)	
Plaintiffs,	)	
	)	
v.	)	No. CIV-85-2434-A
	)	
RICHARD GROSS, M.D., et al.,	)	
	)	
Defendants	)	

ORDER

After hearing argument on defendants' motions to dismiss the amended complaint, and considering all briefs, including supplemental material the Court invited during oral argument, the Court ruled as follows:

1. Plaintiffs' first cause of action is dismissed. The language of 29 U.S.C. § 794, § 504 of the Rehabilitation Act is clear and requires no resort to extrinsic clues for its construction. The proscribed conduct is discrimination against an "otherwise qualified individual" "solely by reason of his handicap." The focus is on the affected individual himself relative to his qualifications for the benefit in question. When the intervention of parental decision, well based on adequate medical briefings or not, necessarily lies in the path of the infant's receipt of the benefit, it cannot be said either that the infant is otherwise qualified or that discrimination is soley because of handicap. In the Court's opinion, defendants properly cite *United States v. University Hospital, State University of New York at Stony Brook*, 725 F.2d 144 (2d Cir. 1984) in support of the proposition that § 504 is inapposite to this case.

2. Plaintiffs' second cause of action is dismissed. The establishment of institutional review boards is authorized pursuant

to 45 U.S.C. § 289(a). However, § 289(c) does not give plaintiffs a cause of action for failure to register a research project without board approval. No private cause of action was created by § 289(a).

3. The Spina Bifida Association of America and the Association for Persons With Severe Handicaps have standing to sue. Defendants' motions are denied as to the associations.

4. Plaintiffs' prayer for injunctive relief will not be stricken.

5. The state doctors have sovereign immunity against plaintiffs' pendent state claims, Counts 9-11, pursuant to *State v. Martin*, 570 P.2d 623 (Okla. 1977).

6. Plaintiffs' constitutional claims are not dismissed.

It is so ORDERED this 22nd day of June, 1987.

WAYNE E. ALLEY
United States District Judge

IN THE UNITED STATES DISTRICT COURT
FOR THE WESTERN DISTRICT
OF OKLAHOMA

Oklahoma City, Oklahoma

DATED: June 29, 1987

CARLTON JOHNSON, et al.,	)	
	)	
Plaintiff(s),	)	
	)	
v.	)	No. CIV-85-2434-A
	)	
RICHARD GROSS, M.D., et al.,	)	
	)	
Defendant(s).	)	

TO: Robert D. Dennis, Clerk of the Court:

Please enter the following minute order in the above-entitled case:

The Court's order dated June 22, 1987 is hereby corrected. Finding #5 should read: "[t]he state doctors have sovereign immunity against plaintiffs' pendent state claims, Courts 10 + 11, pursuant to *State v. Marten*, 570 P.2d 623 (Okla. 1977)."

IT IS SO ORDERED.

WAYNE E. ALLEY
United States District Judge

Counsel Notified _____
Clerk to Notify XX

UNITED STATES DISTRICT COURT
WESTERN DISTRICT OF OKLAHOMA

CARLTON JOHNSON, et al.

v.

RICHARD GROSS, M.D., et al.

JUDGMENT IN A CIVIL CASE

DOCKETED

No. CIV-85-2434-A

[XX] **Jury Verdict.** This action came before the Court for a trial jury. The issues have been tried and the jury has rendered its verdict.

[ ] **Decision by Court.** This action came to trial or hearing before the Court. The issues have been tried or heard and a decision has been rendered.

IT IS ORDERED AND ADJUDGED that Judgment be entered in favor of defendant Dr. Richard Gross and against plaintiff Cheparney Camp on his negligence claim.

That Judgment be entered in favor of defendant Dr. Webb Thompson and against plaintiff Cheparney Camp on his negligence claim.

That Judgement be entered in favor of the defendant Dr. Cynthia Brennan and against plaintiff Carlton Johnson on his negligence claim.

That Judgment be entered in favor of the defendant Dr. John Stuemky and against plaintiff Carlton Johnson on his negligence claim.

November 8, 1990

Date

Clerk
Robert D. Dennis

ENTERED ON JUDGMENT
DOCKET 2-8-90

(By) Deputy Clerk:
Artesia Pennethy

IN THE UNITED STATES DISTRICT COURT
FOR THE WESTERN DISTRICT
OF OKLAHOMA

CARLTON JOHNSON, et al.,	)	
	)	
Plaintiffs,	)	
	)	
v.	)	No. CIV-85-2434-A
	)	
RICHARD GROSS, M.D., et al.,	)	
	)	
Defendants.	)	

AMENDED ORDER OF JUDGMENT

On the 25th date of January, 1990, this action came before the Court for a trial by jury. At the close of all the evidence presented by plaintiffs, defendants moved this court to direct its verdict in favor of the defendants and against the plaintiffs. After hearing arguments and statements of counsel, the Court announced its decision as follows:

> IT IS ORDERED AND ADJUDGED that Judgment be entered in favor of defendant Gregory Herbeck, M.D., and against plaintiffs John and Frieda Smith on their negligence claim.
>
> That Judgment be entered in favor of defendant Jerry D. Razook, M.D., and against plantiffs John and Frieda Smith on their negligence claims.
>
> That Judgment be entered in favor of defendants Richard Gross, M.D., Webb Thompson, M.D., Cynthia Houdesheldt Brennan, M.D., John Stuemky, M.D., Jerry D. Razook, M.D., and Gregory Herbeck, M.D., and against plaintiffs on their claims premised on violations of 42 U.S.C. Section 1983.

The remaining issues have been tried and the jury has rendered its verdict.

IT IS ORDERED AND ADJUDGED that Judgment be entered in favor of defendant Dr. Richard Gross and against plaintiff Cheparney Camp on his negligence claim.

That Judgment be entered in favor of defendant Dr. Webb Thompson and against plantiff Cheparney Camp on his negligence claim.

That Judgment be entered in favor of the defendant Dr. Cynthia Brennan and against plaintiff Carlton Johnson on his neglience claim.

That Judgment be entered in favor of the defendant Dr. John Stuemky and against the plaintiff Carlton Johnson on his negligence claim.

Wayne E. Alley
UNITED STATES DISTRICT JUDGE

ENTERED ON JUDGMENT DOCKET ON MAY 9, 1990.

UNITED STATES COURT OF APPEALS
TENTH CIRCUIT

CARLTON JOHNSON, by Sharon Johnson as his next friend; STONEWALL JACKSON SMITH, deceased, by and through Frieda Smith and John Smith; MELISSA CAMP, deceased, by and through Cheparney Camp; and THE SPINA BIFIDA ASSOCIATION OF AMERICA;

Plaintiffs-Appellants,

and

SHARON JOHNSON; and THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS, individually and on behalf of others similarly situated,

Plaintiffs,

v.

WEBB THOMPSON, M.D., Chief of Staff and Medical Director, Oklahoma Children's Memorial Hospital, in his individual and official capacities; JERRY D. RAZOOK, M.D., Attending Assistant Professor of Pediatrics, Pediatric Cardiology Service, Oklahoma Children's Memorial Hospital, in his individual capacity; GREGORY HERBECK, M.D., Intern Department of Pediatrics, Oklahoma Children's Memorial Hospital, in his individual capacity;

FILED
United States Court
of Appeals
Tenth Circuit

AUG 06 1992

ROBERT L.
HOECKER
Clerk

No. 90-6107

CYNTHIA HOUDESHELDT, M.D., in her individual capacity; RICHARD H. GROSS, M.D., in his individual capacity; WILLIAM R. BURKETT, PATTY EATON, REGINALD BARNES, W.E. FARHA, JOSEPH W. STAFFORD, JANE HARTLEY, VIRGINIA KIDD, JOHN E. ORR, WAYNE C. CHANDLER, Members, Oklahoma Commission for Human Services; ROBERT BONAR, Administrator, Children's Hospital of Oklahoma; ANDREW A. LASSER, C.E.O., Oklahoma Medical Center; RON DORRIS, Chief Operation Officer, Oklahoma Medical Center; LAURA TULL, R.N.; RUTH TATYREK, M.S.W.; JOHN STUEMKY, M.D.; MICHAEL P. MORRIS, M.D.; BENJAMIN DEMPS, JR., Director, Oklahoma Department of Human Services; J. ANDREW SULLIVAN, M.D.; DAVID YNGVE, M.D.; WILLIAM E. BARNES, M.D.; HARRIET COUSSONS, M.D.; and ALAN OLSON, M.D.,

Defendants-Appellants,

and

THOMAS PRATT, M.D., J. PATRICK LIVINGSTON, M.D., and W.J. CRAIG, M.D., in their individual capacities,

Defendants.

Appeal from the United States District Court
for the Western District of Oklahoma
(D.C. No. CIV-85-2434-A)

Larry A. Tawwater of Lampkin, McCaffrey & Tawwater, Oklahoma City, Oklahoma (Ben T. Lampkin and Jo L. Slama of Lampkin, McCaffrey & Tawwater, Oklahoma City, Oklahoma, and James Bopp, Jr., Thomas J. Marzen, and Mary M. Nimz of The National Legal Center for the Medically Dependent and Disabled, Inc., Indianapolis, Indiana, with him on the brief) for Plaintiffs-Appellants Carlton Johnson, Stonewall Jackson Smith, and Melissa Camp.

St. John Barrett, Washington, D.C., on the brief for Plaintiff-Appellant The Spina Bifida Association of America.

Robert C. Margo (John Wiggins and Cynthia L. Sparling with him on the brief) of Short Barnes Wiggins Margo & Adler, Oklahoma City, Oklahoma, for Defendants-Appellees Richard Gross, M.D., J. Andrew Sullivan, M.D., David Yngve, M.D., William Barnes, M.D., Harriet Coussons, M.D., Webb Thompson, M.D., Jerry Razook, M.D., Gregory Herbeck, M.D., John Stuemky, M.D., Alan Olson, M.D., and Cynthia Houdesheldt, M.D..

John G. Fears, Assistant General Counsel, Department of Human Services, Oklahoma Commission for Human Services, Oklahoma City, Oklahoma, for Defendants-Appellants Benjamin Demps, Jr., William R. Burkett, Patty Eaton, Reginald Barnes, W.E. Farha, Joseph W. Stafford, Jane Hartley, Virginia Kidd, John E. Orr, Wayne C. Chandler, Robert Bonar, Andrew A. Lasser, Ron Dorris, Laura Tull, R.N., and Ruth Tatyrek, M.S.W..

Before HOLLOWAY and EBEL, Circuit Judges, and OWEN, District Judge.*

EBEL, Circuit Judge.

This appeal requires us to confront a variety of issues regarding the medical treatment provided to certain infants born with spina bifida. We address primarily whether the infants' rights under the Constitution and under section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794, were violated. The district court entered judgment for the defendants. We affirm.

I. Background

Plaintiffs-Appellants Carlton Johnson, Melissa Camp, and Stonewall Jackson Smith were all born with myelomeningocele ("MM"), a type of spina bifida, at Oklahoma Children's Memorial Hospital ("OCMH"). The appellants allege that they received discriminatory treatment based on their handicap and on their socioeconomic status. The parties sharply dispute many of the facts in this case. However, the record supports the following factual background.

Defendant-appellee Dr. Richard H. Gross led a team of doctors and other health professionals ("the MM team") at OCMH who treated newborn infants with myelomeningocele. This treatment, which includes surgery and the administering of antibiotics, must take place soon after birth. In some cases, however, the infant will not survive even with treatment. In such cases, treating the infant merely prolongs his or her suffering.

In conjunction with his work at the hospital, Dr. Gross performed a study and published an article, entitled *Early Management and Decision Making for the Treatment of*

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* Honorable Richard Owen, Senior District Judge, United States District Court for the Southern District of New York, sitting by designation.

Myelomeningocele, 72 Pediatrics 450 (1983). This study covered the period 1977 through 1982, during which time the MM team evaluated sixty-nine infants born with myelomeningocele. The MM team recommended "vigorous treatment," i.e., surgery and antibiotics, for thirty-six of the infants. One of these infants later died of unrelated causes; the rest survived. The team recommended "supportive care," i.e., no treatment other than making the infants as comfortable as possible, for the remaining thirty-three infants. The parents of five infants in the latter group rejected the recommendations, and three of these infants survived. Several other infants survived without treatment for several months and were subsequently treated. The remaining twenty-four infants receiving supportive care died.

The appellants allege that when the MM team made its recommendations, it considered both medical and nonmedical criteria, the latter including the parents' socioeconomic status. The appellants allege that the MM team discriminated against infants who came from families that the team believed lacked the intellectual and financial resources to provide the appropriate continuing care for a child with MM. According to the appellants, the MM team was more likely to recommend only supportive care for infants from such families. The appellants further allege that the MM team did not inform parents of its consideration of such factors when it made its recommendation. Although the appellees argue that the parents made the ultimate treatment decision, parents of sixty-four of the sixty-nine infants followed the MM team's recommendation. Thus, the appellants argue, the MM team was the true decision-maker.

Melissa Camp and Stonewall Jackson Smith were participants in the study. The team recommended, and each infant received, only supportive care; both died. Carlton Johnson was born after completion of the study, but while the team allegedly continued to use the study's criteria to make its recommendation. The MM team recommended and Johnson received only

supportive care. He survived without treatment for seventeen months, when surgery was finally performed. He was still alive at the time of trial, but suffered a severe mental handicap allegedly due, in part, to the team's failure to treat him immediately.

The hospital changed its practice in 1984. Since then, all infants born with spina bifida have received vigorous treatment, with the exception of one infant for whom treatment clearly would have been futile.

The parents of Camp, Smith, and Johnson, on behalf of their children, together with the Spina Bifida Association of America ("SBAA") and the Association for Persons with Severe Handicaps ("the plaintiffs"), filed suit against the members of the MM team, various other physicians, and a number of state officials. The plaintiffs sought class certification on behalf of 156 potential members, all infants born with MM at OCMH during the pendency of the study and all those born afterward while OCMH allegedly continued to use the study criteria. In their complaint, the plaintiffs asserted causes of action from violations of rights arising under, among other sources, the Due Process Clause, the Equal Protection Clause, section 504 of the Rehabilitation Act of 1973 ("section 504"), and state law. The plaintiffs sought compensatory and punitive damages along with declaratory and injunctive relief.

The district court denied the plaintiffs' application for class certification. In addition, the court dismissed, pursuant to Fed. R. Civ. P. 12(b)(6), the cause of action brought under section 504. It granted summary judgment in favor of the defendants on the claims for declaratory and injunctive relief and accordingly dismissed from the action all defendants against whom the plaintiffs had sought only such relief. The court also granted summary judgment in favor of defendant Dr. Alan Olson.

Trial commenced in 1990 against the remaining defendants on the plaintiffs' claims based on 42 U.S.C. § 1983 and state

common law negligence. Prior to submitting the case to the jury, however, the district court directed verdicts in favor of the defendants on all claims asserted on behalf of plaintiff Stonewall Jackson Smith, all claims asserted against defendants Dr. Gregory Herbeck and Dr. Jerry D. Razook, and all claims asserted under 42 U.S.C. § 1983. The court then submitted Carlton Johnson's and Melissa Camp's negligence claims against the remaining physician defendants to the jury, which found for the defendants.

Camp, Smith, and Johnson, together with the SBAA, filed a timely notice of appeal.[1] We have jurisdiction pursuant to 28 U.S.C. § 1291.

II. Section 504

The appellants argue that the district court erred in dismissing their cause of action under section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794. Because the court dismissed this claim on the pleadings pursuant to Fed. R. Civ. P. 12(b)(6), we review its order de novo. *Ayala v. Joy Mfg. Co.*, 877 F.2d 846, 847 (10th Cir. 1989).

At the time this action was brought, section 504 provided in relevant part:

> No otherwise qualified handicapped individual in the United States, as defined in [29 U.S.C. § 706(7)], shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency . . . .

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[1] For convenience, we will refer to the infants Camp, Smith, and Johnson as "the appellants."

29 U.S.C.A. § 794 (West 1985).[2] Thus, to state a claim under section 504, "a plaintiff must prove (1) that he is a 'handicapped individual' under the Act, (2) that he is 'otherwise qualified' for the [benefit] sought, (3) that he was [discriminated against] solely by reason of his handicap, and (4) that the program or activity in question receives federal financial assistance." *Strathie v. Department of Transp.*, 716 F.2d 227, 230 (3d Cir. 1983) (citation omitted); *see also Rothschild v. Grottenthaler*, 907 F.2d 286, 289-90 (2d Cir. 1990).

The district court held that "[w]hen the intervention of parental decision, well based on adequate medical briefings or not, necessarily lies in the path of the infant's receipt of the benefit, it cannot be said either that the infant is [']otherwise qualified['] or that the discrimination is [']solely['] because of handicap." R., Vol. I, Doc. 158, at 1. The appellants argue that if the MM team's actions rendered parental consent a sham, such "consent" cannot be considered an intervening cause that makes section 504 inapplicable. We agree with this argument by the appellants, but nonetheless conclude that the district court's dismissal of the section 504 claim was proper, albeit for different reasons.

Whether section 504 applies to "individual medical treatment decisions involving handicapped infants" is a controversial issue that the Supreme Court has expressly left open. *See Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 624 (1986) (plurality opinion). The appellants argue that the MM team's conduct constituted discrimination in violation of section 504 based on two principal grounds. They argue primarily that the team recommended only supportive care for Camp, Smith, and Johnson because their families were of low socioeconomic status. They argue secondarily that, in general, the team recommended supportive care for those infants as to whom they

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[2] Section 504 was amended in 1986, after the appellants first filed this action, and again in 1988. Neither amendment substantively affects the meaning of the section as relevant to the instant appeal.

anticipated a greater degree of handicap. In addition, the SBAA makes a third argument that the hospital discriminated against *all* infants born with MM. We deal with each argument in turn.

A. Discrimination Based on Socioeconomic Status

In essence, the appellants argue that but for (1) having spina bifida and (2) being of low socioeconomic status, the MM team would not have recommended that they receive only supportive care. Because of the discrimination based on these two conditions, the appellants assert a violation of section 504. To evaluate their claim, we consider whether the appellants have met section 504's four conditions.

The Supreme Court's decision in *Bowen* establishes that the first condition — that infants born with spina bifida are "handicapped individuals" under the Rehabilitation Act of 1973 — has been met. Although the Supreme Court did not issue a majority opinion in that case, seven Justices agreed that the term encompasses "an infant who is born with a congenital defect." *See Bowen*, 476 U.S. at 624 (opinion of Stevens, J., joined by Marshall, Blackmun & Powell, JJ.); *id.* at 652 (opinion of White, J., joined by Brennan & O'Connor, JJ).

The appellants' complaint fails to satisfy both the second and third conditions. However, for purposes of our holding with regard to these particular allegations, we need address only the third condition, that the discrimination resulted "solely by reason of [the] handicap." 29 U.S.C. § 794. In essence, the appellants argue that the team discriminated against them in relation to other infants with spina bifida because of their low socioeconomic status. Section 504, by its very teams, does not cover discrimination among similarly handicapped persons. *See Clark v. Cohen*, 613 F. Supp. 684, 693 (E.D. Pa. 1985), *aff'd on other grounds*, 794 F.2d 79 (3d Cir.), *cert. denied*, 479 U.S. 962 (1986). The word *solely* provides the key: the discrimination must result from the handicap and from the handicap alone. If others with the same handicap do not suffer the

discrimination, then the discrimination does not result "solely by reason of [the] handicap." Here, the appellants allege that the discrimination resulted at least in part from their low socioeconomic status. That discrimination is not actionable under section 504. Accordingly, we hold that the district court correctly dismissed the causes of action based on those allegations for failure to state a claim under section 504.

B. Discrimination Based on Degree of Handicap

The appellants argue that the MM team "used the anticipated degree of handicap as a basis for recommending that beneficial medical treatment not be provided" and in so doing violated section 504. Corrected Br. in Chief of Appellants Carlton Johnson, Stonewall Jackson Smith and Melissa Camp at 30 [hereinafter Appellants' Br. in Chief]. We reject this argument because the appellants fail to satisfy the second condition of section 504, that they were "otherwise qualified" for the treatment they did not receive.

The "otherwise qualified" langauge, when considered in conjunction with the "solely" language of the third condition, poses a formidable obstacle for anyone alleging discrimination in violation of section 504 based upon the failure to receive medical treatment for a birth defect. Such a plaintiff must prove that he or she was discriminatorily denied medical treatment because of the birth defect and, at the same time, must prove that, in spite of the birth defect, he or she was "otherwise qualified" to receive the denied medical treatment. Ordinarily, however, if such a person were not so handicapped, he or she would not need the medical treatment and thus would not "otherwise qualify" for the treatment.

We agree, therefore, with the Second Circuit's analysis in *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984). In that case, the court considered the application of section 504, and its second requirement in particular, to infants born with multiple birth defects. The court stated that the term *otherwise*

qualified cannot ordinarily be applied "in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being 'otherwise qualified' to have corrective surgery performed." *Id.* at 156. The court reasoned, "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say . . . that a particular decision was 'discriminatory.'" *Id.* at 157.[3]

C. Discrimination Against All Infants with MM

The SBAA argues that the team discriminated against all infants with MM by designating them as subjects of a medical research project without their parents' knowledge or consent. Because all infants with MM were part of the study during its pendency, the SBAA contends the discrimination was "solely" due to the handicap, thereby meeting the third condition.

Under this argument, the appellants still fail to satisfy the

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[3] Several jurists have hypothesized situations in which the handicap that forms the basis for the section 504 discrimination bears no relation to the medical treatment sought but denied. For example, Justice White stated in *Bowen*:

> An esophageal obstruction, for example, would not be part and parcel of the handicap of a baby suffering from Down's syndrome, and the infant would benefit from and is thus otherwise qualified for having the obstruction removed in spite of the handicap. In this case, the treatment is completely unrelated to the baby's handicapping condition. If an otherwise normal child would be given the identical treatment, so should the handicapped child if discrimination on the basis of the handicap is to be avoided.

Bowen, 476 U.S. at 655 (footnote omitted) (White, J., dissenting); *see also University Hospital*, 729 F.2d at 162 (Winter, J., dissenting). We do not decide whether section 504 might apply in such a situation, but it would seem that the "otherwise qualified" condition might be satisfied under such a scenario. *See Glanz v. Vernick*, 750 F. Supp. 39, 45-46 (D. Mass. 1990) (AIDS patient denied treatment for ear perforation stated claim under section 504). We do not find such a situation here.

second condition. The infants required the medical treatment sought only because they were born with MM. Thus, they were not "otherwise qualified" to receive the medical treatment denied to them because of the alleged discrimination.

Section 504 proscribes discrimination between the nonhandicapped and the "otherwise qualified" handicapped. It does not create any absolute substantive right to treatment. As the plurality stated in *Bowen*, "'Section 504 seeks to assure evenhanded treatment'; 'neither the language, purpose, nor history of [section] 504 reveals an intent to impose an affirmative-action obligation' on recipients of federal financial assistance." *Bowen*, 476 U.S. at 640 (plurality opinion) (citations omitted). The plurality also noted that "nothing in the legislative history . . . even remotely suggests that Congress contemplated the possibility that 'section 504 could or would be applied to treatment decisions[] involving defective newborn infants.'" *Id.* at 645 n.33 (citation omitted; alteration added). Without a showing that the nonhandicapped received the treatment denied to the "otherwise qualified" handicapped, the appellants cannot assert that a violation of section 504 has occurred.

In sum, we hold that the appellants failed to state a claim for violation of section 504 and that the district court therefore did not err in dismissing the claim brought under this section.

III. Section 1983

In their complaint below, the appellants asserted that discrimination based on socioeconomic factors violated their procedural due process and equal protection rights, that the MM team's failure to provide vigorous treatment violated their substantive due process rights, that discrimination on the basis of handicap violated their rights under section 504, and that the MM team's recommendations deprived the parents of the opportunity to make decisions regarding their children's care in violation of their fundamental right to privacy. For each of these alleged violations of federal rights, the appellants brought a cause of action under 42 U.S.C. § 1983. The district

court granted the appellees' motions for directed verdicts on all of these causes of action. The appellants now argue that the district court erred in doing so.

We review de novo the district court's ruling on a motion for directed verdict. *Hill v. Goodyear Tire & Rubber, Inc.*, 918 F.2d 877, 880 (10th Cir. 1990). We look to the record to see if the evidence, construed in the light most favorable to the nonmoving party, supports only one resolution of the issue. *See Ralston Dev. Corp. v. United States*, 937 F.2d 510, 512 (10th Cir. 1991).

A. Discrimination on the Basis of Socioeconomic Status

The appellants argue that discrimination on the basis of socioeconomic status violates their right to due process and equal protection. The district court directed a verdict on this issue after concluding that no evidence supported the claim:

> The article makes reference to socioeconomic factors as being considered, theoretically, but we don't have any evidence here that the children who were selected for [vigorous] treatment enjoyed a socioeconomic status any different from the ones that were recommended for supportive [care]. We don't have any evidence that wealthy parents' babies lived and poor parents' babies died; we don't have any evidence of a racial basis or anything other than a medical determination based upon degree of handicap and not on mere presence of handicap.

R., Vol. XX, at 592.

On appeal, the appellants argue that "[t]he constitutional right to be free from discrimination requires no citation." Appellants' Br. in Chief at 38. However, the district court did not direct a verdict because of a defect in the appellants' legal theory — it directed the verdict because of a lack of evidence. The appellants do not point us to any evidence that the district court may have overlooked. Indeed, they do not discuss the evidence at all.

The appellants presented as evidence only Dr. Gross' article, which indicates that the MM team considered socioeconomic factors in making its recommendation. However, the appellants presented no evidence that these factors affected the outcome of the recommendations in their individual cases. In other words, there is no evidence to establish that the appellants' socioeconomic status was a factor that caused the recommendation that they receive only supportive care. After our review of the record, we therefore agree with the district court that the appellants presented no evidence of discriminatory harm and that the district court correctly granted the motion for a directed verdict.

B. Substantive Due Process

The appellants argue that the appellees' conduct violated their substantive due process rights by depriving them of their liberty interests in their own lives. Because of this deprivation, the appellants urge us to reverse the district court's decision to direct a verdict for the appellees on the appellants' section 1983 claim based on substantive due process.

The Due Process Clause does protect an interest in life. *E.g.*, *Cruzan v. Director, Missouri Dep't of Health*, 110 S. Ct. 2841, 2853 (1990). It does not follow, however, that the state necessarily has a constitutional duty to take affirmative steps to preserve life. In *DeShaney v. Winnebago County Department of Social Services*, 489 U.S. 189 (1989), the Supreme Court explained:

> The [Due Process] Clause is phrased as a limitation on the State's power to act, not as a guarantee of certain minimal levels of safety and security. It forbids the State itself to deprive individuals of life, liberty, or property without "due process of law," but its language cannot fairly be extended to impose an affirmative obligation on the State to ensure that those interests do not come to harm through other means.

Id. at 195.

In effect, the appellants argue that substantive due process implies a right to treatment. Such a right exists only in narrow circumstances, however. Specifically, "when the State takes a person into its custody and holds him there against his will, the Constitution imposes upon it a corresponding duty to assume some responsibility for his safety and general well-being." *Id.* at 199-200 (citations omitted); *see Youngberg v. Romeo*, 457 U.S. 307, 324 (1982) (involuntarily committed mental patient entitled to adequate medical care).

Infants born with spina bifida do not fall into the above category; accordingly, such infants cannot claim a constitutional right to treatment. Without such a right, the appellants cannot claim a deprivation of their liberty interest if the state failed to treat them. *Cf. DeShaney*, 489 U.S. at 196-97 ("If the Due Process Clause does not require the State to provide its citizens with particular protective services, it follows that the State cannot be held liable under the Clause for injuries that could have been averted had it chosen to provide them.") (footnote omitted).

The fact that the state did provide some medical services does not alter this analysis. The First Circuit recently stated in an analogous situation involving a section 1983 claim:

> Although the [state] may have played some causal role in the harm, it did so only because [the plaintiff] voluntarily availed himself of a [state] service. The [state] did not force [the plaintiff], against his will, to become dependent upon it. Thus, the [state's] action, while possibly negligent or even willfully indifferent or reckless, did not take on the added character of violations of the federal Constitution.

Monahan v. Dorchester Counseling Center, Inc., 961 F.2d 987, 993 (1st Cir. 1992). Similarly, the fact that the appellants had received some medical benefits at OCMH did not entitle them to further treatment based on substantive due process.

We accordingly affirm the district court's decision to grant a directed verdict for the appellees on the appellants' section

1983 cause of action for violation of their substantive due process rights.

C. Section 504

The appellants assert a violation of their rights under section 504. We held in Part II of this opinion that no violation occurred, even taking all of the appellants' allegations as true. We therefore hold that the district court did not err in directing a verdict for the appellees on the appellants' section 1983 claim for violation of rights secured by section 504.

D. Parental Rights

The parents argue that the MM team deprived them of the right to choose what type of medical care their children should receive. They contend that this right is inherently part of the right to privacy protected by the Fourteenth Amendment. Thus, they argue, the district court erred in directing a verdict for the appellees on their section 1983 cause of action for violation of their right to privacy.

The parents did not file a notice of appeal in their own right, however, but rather took this appeal only as representatives of the infants. If a party's name does not appear in a timely filed notice of appeal, that party has not appealed any adverse judgment. *Torres v. Oakland Scavenger Co.*, 487 U.S. 312, 314-18 (1988). The parents therefore are not parties to this appeal except as representatives of the infants,[4] and they have no standing to assert claims on their own behalf. Accordingly, we have no jurisdiction to hear the parents' argument regarding violation of their own rights.

IV. Denial of Discovery of Identities of Study Participants

The appellants argue that the district court erred in denying their motion to compel discovery of the names of all partici-

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[4] Sharon Johnson, Carlton Johnson's mother, originally appeared as a plaintiff. She voluntarily dismissed her claims without prejudice and is no longer a party except as a representative of her son. *See* R., Vol. V, Doc. 469, at 2.

pants in the MM team's study. We review orders relating to discovery for an abuse of discretion. *See Willner v. Budig*, 848 F.2d 1032, 1035-36 (10th Cir. 1988), *cert. denied*, 488 U.S. 1031 (1989). We hold that the district court did not abuse its discretion in denying the motion.

The magistrate who initially decided the appellants' motion concluded that the privacy interests of the other study participants outweighed the appellants' need for the information. The appellants appealed this decision to the district court, which upheld the magistrate's judgment.

The appellants argue that the information sought went to the heart of their allegations. The appellants presented the MM team's article as preliminary evidence. The members of the team contend, however, that they did not actually make "recommendations" to the parents, but rather only presented options to them, and that they did not actually base medical decisions on socioeconomic data. Thus, the appellants sought testimony from other study participants to show the existence of a concerted plan to use socioeconomic criteria in making recommendations for appropriate treatment and to refute the appellees' contention that they merely presented options to parents who made the final choice. To obtain such testimony, the appellants sought to learn the identities of these other participants.

The decision whether to administer heroic life-sustaining treatment to a severely handicapped newborn is one of the most heartwrenching decisions a parent can be called upon to make. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 396-97 (D.D.C. 1983). Parents who have had to make such a decision are entitled to privacy and confidentiality. We believe that the magistrate was correct to balance the relevance and necessity of the information the appellants requested against the rights of other participants to maintain their privacy. *See Lukaszewicz v. Ortho Pharmaceutical Corp.*, 90 F.R.D. 708, 709 (E.D. Wis. 1981).

The appellees did provide information about the care rendered to each participant in the study. However, the appellees did not disclose the identities of the other infants. Thus, if the appellants desired to impeach the appllees' representations regarding treatment to those other infants, the appellants had to ascertain the identities of the infants' families through other means. That no doubt presented a difficult — perhaps impossible — task for the appellants. Nonetheless, given the important interests of the other infants and their families to preserve the confidential nature of their contacts with the physicians and the hospital, we cannot say that the magistrate abused his discretion in refusing to order this discovery.

V. Other Issues

The appellants raise a number of other issues, which we need only discuss briefly.

A. Statute of Limitations

The appellants argue that the district court erred in submitting to the jury the issue of whether Melissa Camp's negligence claim was time-barred. Because her father testified without contradiction that he did not learn of the MM team's actions until 1986, the appellants argue that the district court should have directed a verdict on this issue in favor of Melissa Camp. Instead, the court submitted the issue to the jury, which decided that Melissa Camp's claims were barred by the statute of limitations.

Under Oklahoma law, the relevant statute of limitations requires that a plaintiff bring a suit within "two years from the date [the] plaintiff knew or should have known, through the exercise of reasonable diligence[,] of the existence of the death, injury or condition complained of." *Redwine v. Baptist Medical Center of Okla., Inc.*, 679 P.2d 1293, 1295 (Okla. 1983). Moreover, "[w]hether plaintiff exercised 'reasonable diligence' in ascertaining the cause of . . . death is a question of fact to be determined by the jury." *Id.* Because the issue was not when Melissa's father learned of the relevant facts, but rather when

he should have learned of them, the district court properly denied the motion for a directed verdict.[5]

B. Class Certification

The appellants content that the district court erred in denying their application for class certification. We review the district court's decision for abuse of discretion. *Pilots Against Illegal Dues v. Air Line Pilots Ass'n.*, 938 F.2d 1123, 1134 (10th Cir. 1991). The district court held that the number of infants denied vigorous treatment was too small to meet the numerosity requirement of Fed. R. Civ. P. 23(a)(1). Given our deferential standard of review, we cannot say that the court's decision was in error. *See Rex v. Owens*, 585 F.2d 432, 436 (10th Cir. 1978) ("no set formula" to determine whether numerosity requirement was met; instead, this is a fact-specific inquiry best left to the discretion of district court).

C. Declaratory and Injunctive Relief

The appellants argue that the district court erred in granting summary judgment to the appellees on the claims for declaratory and injunctive relief. Declaratory relief is discretionary, *Green v. Mansour*, 474 U.S. 64, 72 (1985), and we find no abuse of that discretion in the court's declining to exercise jurisdiction over the appellants' claims for such relief. With regard to injunctive relief, we agree that the district court that the appellants' failure to present any evidence of continuing discrimination since 1984 renders concerns of future recurrence purely speculative. We therefore affirm the district court's grant of summary judgment on these issues.

D. Jury Instructions

The appellants argue that the district court instructed the jury incorrectly regarding the differing standards of conduct applicable to appellees Dr. Gross and Dr. Thompson. We find no error in the district court's reliance on *Fox v. Oklahoma Memo-*

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[5] In view of our resolution of this issue, the appellee's Motion to Strike Juror Affidavit and Request for Corrected Brief in Chief is moot.

rial Hospital, 774 P.2d 459 (Okla. 1989), which held that a plaintiff must show gross negligence to overcome the sovereign immunity enjoyed by a physician employed at a state hospital at the time of Melissa Camp's birth. *Id.* at 461. Furthermore, the court specifically explained to the jury that it was to apply a different standard of negligence to Carlton Johnson's claims because they arose at a time when Oklahoma law was different. *See* R., Vol. V, Doc. 480, Instruction No. 15.

The appellants also challenge the adequacy of the informed consent instruction given to the jury. However, the appellants failed to object to the instruction below, and on review we do not find the instruction to be plain error.

E. Summary Judgment for Dr. Olson

The appellants appeal the district court's denial of their motion for reconsideration of the dismissal of appellee Dr. Alan Olson on summary judgment. The standard of review for the denial of a motion for reconsideration depends on the nature of the underlying decision. *See Federal Kemper Ins. Co. v. Rauscher*, 807 F.2d 345, 348-49 (3d Cir. 1986). In this case, because the motion was for reconsideration of summary judgment, our review is de novo. *Applied Genetics Int'l, Inc. v. First Affiliated Sec., Inc.*, 912 F.2d 1238, 1241 (10th Cir. 1990). After reviewing the record, we agree with the appellees that Dr. Olson's status as an attending physician did not connect him sufficiently to the treatment decisions made and that summary judgment was appropriate.

F. Directed Verdicts for Dr. Herbeck and Dr. Razook

The appellants argue that the district court incorrectly directed verdicts for appellees Dr. Herbeck and Dr. Razook regarding the decision to administer supportive care to Stonewall Jackson Smith. The appellants had argued below that Smith's mother was not given informed consent to withhold vigorous treatment.

Under Oklahoma law, a plaintiff must prove the injury

resulted in order to present a prima facie case of breach of duty to inform. *Scott v. Bradford*, 606 P.2d 554, 557-59 (Okla. 1979). The appellees sought to avoid liability by showing that Smith would not have survived even with vigorous treatment. In support, they introduced evidence that Smith suffered from anencephaly, a congenital absence of the brain; when such a condition is present, an infant cannot survive with or without treatment.

In response, the appellants introduced evidence that the test the appellees used to test for anencephaly was not always accurate. They also introduced testimony that Smith might have survived if the test were inaccurate and he did not have anencephaly. The appellants presented no evidence, however, that the test was in fact inaccurate in this particular case or that Smith would have survived. They therefore failed to show that an injury resulted from the lack of informed consent, as required under *Scott*. Under these circumstances, we affirm the district court's decision to direct a verdict.

G. Other Rulings

The appellants challenge various evidentiary rulings and a ruling denying a mistrial. After reviewing the record, we find no abuse of discretion of these rulings.

The appellants also list several other issues in their "Statement of the Issues," but fail to brief them. In general, we do not address issues not briefed. *See American Airlines v. Christensen*, No. 91-4047, 1992 U.S. App. Lexis 13614 at *14, n.8 (10th Cir. June 17, 1992) ("It is insufficient merely to state in one's brief that one is appealing an adverse ruling below without advancing reasoned argument as to the grounds for appeal.") (citing Fed. R. App. P. 28(a)(4), recodified as Fed. R. App. P. 28 (a)(5)).

VI. Conclusion

Because we hold that the district court committed no reversible error, we AFFIRM its judgment.